Conference proceedings

Mercure Hotel, Sydney
November 9th–10th 2001

Forging our Future

CONSUMER ADVISORY GROUP
NSW CAG

Mental Health Inc

Mental health is an expanding field and one of great unmet need. There have been many sad and traumatic times for those who have experienced mental illnesses as well as for their families and loved ones. Services provided have undergone great change and reform but there is still the need for further development as well as responsiveness to emerging needs. These include recognition of the growing levels and severity of problems in children and young people, the complex and negative interactions of drug and alcohol problems with mental health and the needs of our ageing population. Mental health problems are extensive and pervasive and have powerful impact. Mental health is, and must be, "everybody's business".

There are, however, great achievements to be celebrated in mental health and among the best of these are the recognition, roles and leadership of consumers and carers and the growth of their participation in all aspects of mental health care. This movement is thriving, hopeful, energetic and enthusiastic and has much to share and teach others.

Mental health is no longer a system of passive reception of care, but rather an increasingly meaningful and effective two-way interaction with the clinician. The importance of "the concept of health professionals learning from consumers and carers" is now widely acknowledged and informs service planning, care delivery and evaluation.

This report Forging our Future, reflects the landmark conference of NSW consumers and carers where all the challenges of consumer and carer participation are addressed.

Many different models are described and put forward showing their adaptability and power in a wide range of service settings. The abstracts and papers included and the stimulus of the meeting itself reflect the highest quality and show the richness and diversity that comes from consumer and carer participation. Of startling beauty too, is the National Standards Quilt, demonstrating not only the significance of these standards for people who experience a mental illness and their families, but also their major role in setting the targets for the service system and care attainment both now and in the future. The Quilt will not only be a symbol of the creativity of those consumers and carers who contributed to its development, but also a valuable contribution to educating service providers and the community about the importance of these standards to care.

Forging our Future was a hopeful and exciting conference as this report shows. It shows very clearly the innovation, enthusiasm, strengths and commitment to a positive future that consumers and carers bring. This energy will not be lost but will help us all to better mental health, and better futures. It will do so through the powerful contributions that consumers, carers and families have forged to play their part in their own destiny.

Beverley Raphael

Director, Centre for Mental Health

AM, MBBS, MD, FRANZCP, FRCPsych, FASSA, Hon MD (Newcastle NSW)

Reading back through these papers and abstracts brings back fine memories of two days of conferencing by consumers and carers. Reading through these conference proceedings is to be privileged to share the insights and lessons from a wide range of individual's journeys undertaken because of the experience of mental illness. Whether they are the work of carers or consumers they reflect lives lived deeply and lessons hard won.

Here are adventures of soul and mind that are perhaps hard for those not affected by mental illness to understand in their fullness. These writings reflect so many individual struggles and personal achievements in the face of illnesses that at times can be so disabling. Struggles with stigma, ignorance and the greed of spirit that still so often marginalises those who experience a mental illness or psychiatric disorder.

For those of us who have proudly worn the labels of consumer, survivor or carer, the two days of conferencing were a triumph and testimony to the possible as regards to true empowerment. The days were a wonderful chance to exchange our learnings and a chance to experience advocacy at its best: to find common ground in shared experience and to renew hope and find fresh insights and inspiration for our lives and work. The publication of these papers gives us a point of reference as this was the first Consumer Advisory Group conference in NSW. It will also extend the knowledge and stories of the participants to a wider audience and hopefully offer encouragement, ideas and a source for reflection to a new generation of consumers and carers.

I applaud the efforts of all those who presented at the conference and those who did the hard work of organising. This publication celebrates your efforts and gives those like me who read it new expectations for future directions in our sharing of experience about mental health to a wider community.

Simon Champ

Consumer Activist and Director, SANE Australia

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Doug Holmes
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Joan Wakeford

introduction

In mid 2001 I was asked to assist the NSW CAG with their conference, **Forging Our Future,** planned for November. The subsequent months gave me one of the most personally and professionally satisfying assignments in a long career. It was a wonderful time.

The energy, passion and creativity of everyone involved, coupled with their actions in embracing and valuing everyone and every opinion, made the CAG conference very special. It was a genuine celebration of life and the special struggles and triumphs of people with a mental illness or caring for a person with mental illness.

NSW Health Minister Craig Knowles MP and Professor Beverley Raphael, Director, NSW Centre for Mental Health contributed to the sense of occasion with their sensitive and challenging opening addresses and their genuine interest in the conference and its outcomes. Professor Raphael unveiled the CAG NSW Quilt—a collaborative work from across the state—depicting the National Mental Health Standards. This Quilt became a centrepiece of the conference: it was a credit to the creators and everyone who worked on it.

Arana Pearson and Nicholas Yu were inspired choices as keynote speakers, with both Arana and Nick contributing in a huge way to the conference's success.

My special thanks to the members of NSW CAG and the conference committee. You were a real pleasure to work with and I was delighted to work with you in this conference and to share the incredible energy generated by the delegates.

These conference proceedings give examples of the quality of the conference presentations. However they can never convey the energy, the atmosphere and the real celebration that filled the halls, conference rooms and lobbies of the Mercure Hotel on 9–10 November 2001.

Chris Cunliffe-Jones

conference programme

Day 1: Friday 9 November

9.30–10.00am	**Registration**
10.00–10.40am	**Conference Opening**
	• Chairperson
	• Professor Beverley Raphael Director, Centre for Mental Health
	• Hon. Craig Knowles MP, NSW Minister for Health
10.40–11.00am	**Traditional Welcome**
11.00–11.20am	**MORNING TEA**
11.20–12.20pm	**Keynote Speaker**
	Arana Pearson
12.20–12.30pm	**Consumer to Citizen Introduction**
	Paula Hanlon and Douglas Holmes
12.30–1.30pm	**LUNCH**
1.30–2.00pm	**Keynote Speaker**
	Leonie Manns: Recollections of a Churchill Fellow
2.00–3.15pm	**Models of Participation: Concurrent Sessions**
	Grand Central — Consumer Groups in Area Mental Health Services
	Museum — Family Concerns
	Wynyard — Moments and Turning Points
3.15–3.45pm	**AFTERNOON TEA**
3.45–5.00pm	**Models of Participation: Concurrent Sessions**
	Grand Central — Research and Education
	Museum — Collaborations
	Wynyard — Quality
5.30–7.00pm	**CONFERENCE RECEPTION**

conference programme

Day 2: Saturday 10 November

9.00–9.30am	**Registration**
9.30–10.30am	**Keynote Address**
	Nicholas Yu Carers
10.30–11.00am	**MORNING TEA**
11.00–12.00pm	**Consumer to Citizen Workshops**
12.00–1.00pm	**LUNCH**
1.00–2.00pm	**Keynote Presentation: Dance**
2.00–2.15pm	**Consumer to Citizen Feedback**
2.15–3.15pm	**Models of Participation Concurrent Sessions**
	Grand Central Carers
	Museum Youth Symposium
	Wynyard Creative
	Martin Place Participation and Advocacy
3.15–3.45pm	**AFTERNOON TEA**
3.45–4.15pm	**Arana Pearson Reflects**
4.15–4.45pm	**A Minute with Mike**
4.45–5.00pm	**Traditional Farewell**
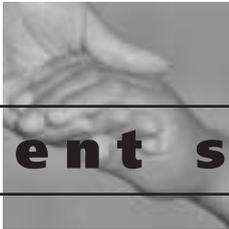
concurrent sessions

Friday 9 November 2.00pm–3.15pm

Session 1	**Consumer Groups in Area Mental Health Services**	
1.1	Northern Sydney Mental Health Consumer Network	Desley Casey
1.2	Consumer Participation in Central Sydney	Peter Schaecken
1.3	Western Sydney Area Mental Health Service Consumer Network	Jodie Brown
1.4	CANDO: Developing Consumer Participation in a Rural and Remote Area Health Service	Douglas Holmes
1.5	Ryde Consumer Network:A Service in Partnership	Paula Hanlon
		Michael Appleton

Session 2	**Families and Mental Health**	
2.1	Children Living with Parents Who Have a Mental Illness	Margaret Cook
2.2	More Than a Handshake	Maggie Lawson

Session 3	**Moments and Turning Points**	
3.1	Mind Matters Magazine	Nicky Cheshire
3.2	A Celebration of Recovery and Community Participation	Leanne Nicholas
3.3	Personal Stories: How to use them as an effective training tool	
		Gary Platz
3.4	Mental Illness Need Not be a Barrier in Reaching Meaningful Employment	Rick Austin

Friday 9 November 3.45pm–5.00pm

Session 4	**Research and Education**	
4.1	CEO-MHS: Forging Our Future Through Evaluation	Gillian Malins
		Jon Strang
		Gordon Lambert
4.2	The NISAD Schizophrenia Research Register: Citizen Profiles	
		Jim Sheedy
4.3	What is the Mental Health Information Service?	Linda Berrigan
4.4	People Like Us: the Issues and the Opportunities: What Works?	
		Leanne Pethick

Session 5	**Collaborations**	
5.1	Resistance and Change: What this might mean for the consumer	
		Martyn Wilson
5.2	Who's Really Learning?	Paula Hanlon
		Laraine Toms

5.3	Consumer Participation in the Support Group Project	Kate Maclean
		Yvette Cotton
		Jan Monson
		Nina Walton
5.4	From Start to Stability: Rebuilding Personal and Community Hope	
		Tony Humphrey

Session 6	**Quality**	
6.1	I'm Made to a High Standard	Desley Casey
6.2	COAT: Developing a Consumer-Oriented Audit Tool for the National Standards for Mental Health Services	Douglas Holmes
6.3	Gissing House Rights Booklet	Kylie Wilson
6.4	Triumph Over Phobia and OCD (TOP NSW)	Linda Junee

Saturday 10 November 2.15pm–3.15pm

Session 7	**Carers**	
7.1	A Carer's Climb to Confidence	Elizabeth Ingram
7.2	Advocacy: When tea and sympathy are not enough	Laraine Toms

Session 8	**Youth Symposium**	
8.1	Australia's Young People: A resource rather than a problem	
		Ann Dadich
8.2	Panel Discussion - Dual Diagnosis and Prevention (Research in Prevention)	
		David Whealing
8.3	Workshop on Youth Issues	

Session 9	**Creative**	
9.1	Healing Tears	Linette Bone
9.2	COW: Consumer Organised Work Cooperative Developing a Consumer Cooperative for Consumers by Consumers	Peter Gates
9.3	Consumers in the Arts (CITA)	Lynda Hennessy

Session 10	**Participation and Advocacy**	
10.1	History and Importance of Advocacy in New Zealand	Suzy Stevens
10.2	You Get Splinters Sitting on the Fence	Maggie Lawson
10.3	Grass Roots and the "Pure Consumer Perspective"	Gary Platz
10.4	Establishing CAG in Griffith	Margaret Mortlock

keynote address

Where we have come from, where are we going to? Visioning for people pursuing recovery and partnership after mental illness.

Arana Pearson, B.A.

Consumer Advisor, Mental Health Commission , New Zealand

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Mental Health Commission vision statement
Our vision is for New Zealand to be a place where people with mental illness have personal power, full participation in their communities and access to a fully developed range of recovery-oriented services.

Mental Health Commission mission statement
To take a lead, through advice, monitoring and promotion, to build a country where people with mental illness, the services they use and the communities they belong to, are able and willing to contribute to their final recovery.

ABSTRACT:

"Consumer" identity is currently about people who are defined in relation to their mental health service use. In order for significant progress to be made in the near future there needs to be a grounded and articulate challenge to the identifying of this subculture that at present is lensed through the telescope of professionalised health services. In part, this means the mental health services working in an authentically public health manner and supporting "consumer" empowerment to truly partner across a range of sectors outside health. Given Australia and New Zealand are both western democracies, the essential elements (or sectors) of the population include a free press (media), a representational political system and structure which is mandated by free elections by the participating constituency (i.e. the population), a publicly funded government sector, a non government organised (third sector), freedom of artistic expression, free market business and entrepreneurial initiative, and voluntary association and activity. "Consumer" spheres of activity are traditionally peer support, peer advocacy, self help and sector participation. A revolution in mental health will express itself when former "mental health consumers" find a voice to redefine themselves and the problem rather than accepting definition and labels of themselves in relation to mental health service use. This may happen as a consequence of active participation and exploration of strengths and contribution within sectors other than health such as business, government, media, voluntary and arts spaces within the community.

Acknowledgement: To the people whose ancestral land this is, the Eora Nation on this Gadigal land, Aboriginal land.

son of mine

I could tell you of heartbreak, hatred blind   *But I'll tell instead of brave and fine*
I could tell of armies that shame mankind,   *When lives of black and white entwine,*
Of brutal wrong and deeds malign,   *And men in brotherhood combine –*
Of rape and murder, son of mine;   *This would I tell you, son of mine.*

by Oodgeroo Noonunccal

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INTRODUCTION

There is a process those of us in the "consumer" movement all understand. It involves our first steps into a service, our first diagnosis, and our experiences of discrimination surrounding mental illness. These experiences are all harrowing but they do not hold equal weight. The experience of discrimination perhaps has the greatest impact for it isolates us from our communities and indeed from ourselves, ultimately denying us a sense of belonging in society.

Ideals of western free democracy define Australasian culture and essential to these ideals are freedom of artistic expression and media; freedom of thought and association; freedom of business enterprise; and political representation through mandate by the population. These ideals have deeply rooted historical foundations which have resulted in myriad forms of public policy. In our part of the world we saw the emergence of the "safety net", a publicly funded mechanism to protect society's most vulnerable people. The provision of Mental Health Services can be conceived as part of this historical development.

Many of us who are involved in the "consumer movement" find ourselves caught in an identity crisis. Mental health services overpower us, define us, and prescribe what we should be. Our identities become confused. Self-definition becomes difficult. Over time our identity becomes synonymous with how services choose to define us. This identity is such a powerful one that it is hard to shake, even after we have left the service as a consumer and return as consumer advisors, advocates or for the purpose of peer support. A barrier emerges with this prescribed identity. It limits our participation into other sectors of society.

Part of my future vision includes an exploration about the ways people with experience of mental illness could contribute to society as we attempt to redefine our own identity and give social value and meaning to the negatively labelled experiences of "mental illness".

1.WHERE HAVE WE COME FROM?

So here I am, in the middle way, having had twenty years—
Twenty years largely wasted, the years of l'entre deux guerres—
Trying to learn to use words, and every attempt
Is a wholly new start, and a different kind of failure
Because one has only learnt to get the better of words
For the thing one no longer has to say, or the way in which
One is no longer disposed to say it. And so each venture
Is a new beginning, a raid on the inarticulate
With shabby equipment always deteriorating
In the general mess of imprecision of feeling,
Undisciplined squads of emotion. And what there is to conquer
By strength and submission, has already been discovered
Once or twice, or several times, by men whom one cannot hope
To emulate — but there is no competition—
There is only the fight to recover what has been lost
And found and lost again and again: and now, under conditions
That seem unpropitious. But perhaps neither gain nor loss.
For us, there is only the trying. The rest is not our business.

T.S. Eliot, East Coker V

For me, it has been nearly twenty years since I was first admitted to hospital. My hospital experience was so harrowing that I have yet to "recover what [had] been lost". It was not only my mental illness that disenfranchised me. It was also the hospital experience. Perhaps this is my personal experience and cannot be read as a comment on all experiences. And mental health services are in a significant development that is ongoing. However, some of our experiences of hospital use are universal.

When people enter mental health services they assume a role in relation to that service. People become "consumers", "clients", and "service users". Moreover, once diagnosed, people are labelled further. They become a schizophrenic, bipolar or whatever label seems diagnostically relevant. These labels and indeed the process one goes through is stigmatising. First, mental health services are unique in that they capture the same social disapproval as prisons. There is no pity or understanding. It is not like being poor or homeless. To be a mental health "consumer" is to be a social pariah. Secondly, once inside a service people are diagnosed. The process of being diagnosed serves to compound the level of social stigma. Oddly, the medical process of diagnosis is intended to be helpful but words like "schizophrenia" have taken on a life of their own in popular culture. It is now associated with violence and unpredictability.

There emerges a depersonalisation process with layers of complexity; a person becomes a label and the label defines a role. In these roles, people leave behind their active citizenship and become passive "recipients of service"; their abilities and attributes no longer acknowledged. The focus becomes their illness, their perceived deficiency. Historically medical professionals have assumed the right to define the problem when people search for meaning and help, and from the medical viewpoint the problem resides within the individuals themselves (Ballard 1994 p 18).

John McKnight, an American analyst and defender of the community concept, suggests that communities are disabled and disempowered when professional services are resourced to provide solutions to a specific community problem. He articulates clearly the effect of this idea on individual citizenship and communities, suggesting:

When the capacity to define the problem becomes a professional prerogative, citizens no longer exist. (p 49)

We can see therefore that to be diagnosed is to be disenfranchised. The everyday experience of disenfranchisement is experiences of discrimination, which derive from the stigmatising effects of mental illness and service delivery.

2. WHERE ARE WE NOW?

You don't get harmony when everyone sings the same note Doug Floyd

The emergence of the consumer movement

Those of us involved in the consumer movement are discovering a wide variety of roles from which to contribute, both within and without the health context. Our diverse experiences of "illness" are challenging and wide-ranging but within this diversity and challenge lay the foundations of the consumer movement. We can map the development as follows:

Firstly, the patients' rights movement was initiated around the beginning of the 20th century and this was

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dominated by advocacy work, which used awareness raising as their main activity. The legal framework was also used to protect mental health service users; a group seen as vulnerable to human rights abuses.

The idea of "consumer rights" did not emerge until the mid 20th century (Tomes, 1998) with a focus on quality improvement of services and service development along the lines of a business. Consumer participation and advisory work today often revolves around the areas of consumer rights and quality systems improvement. Perhaps this is best summarised as "peer advocacy".

Another type of service user movement is that of "peer support". Here, service users embrace their diagnosis and seek to assist other people with similar problems. Peer support often seeks to inform the professional sector about developments that may help service users, such as self help and health sector participation. As one would expect, peer support focuses heavily on the issue of diagnosis as identity and how this identity impacts on service users.

Internationally, consumer movements tend to be driven from a peer support and independent self help model (Kaufmann, C 1995, Van Tosh & Paolo D Vechhio circa 1996), the foundations of which lie with organisations like Alcoholics Anonymous, which formed in the 1930s. Other service user developments have initiated programmes such as "Grow", a twelve step mental health recovery initiative formed in Australia in 1957. "Grow" started in New Zealand in 1963 and has since spread worldwide with some degree of success (Grow NZ).

The peer support initiatives described above are mainly voluntary with agreed procedures about non-professional and non-affiliation with other organisations for the sake of focus and clarity of purpose. "Talking" as therapy is the general theme surrounding most of these groups. "Talking therapies" being the main initiative within services.

Problems with the consumer movement

Although consumer involvement is seen as an integral part of mental health services today problems are still clearly evident. Independent peer advocacy, for example, is largely under funded although most would agree that it is essential to a robust culture of recovery. Moreover, most of this activity is voluntary. And although the Health and Disability Commission Act provides a code and system for complaints in New Zealand, most of the "agents" of the Commission, who are given the role of advocate, are not themselves consumer workers and they may not understand the mental health sector at all. There are similar issues in Australia.

The complexity of the advocacy movement is evident. I can identify several types of advocacy. These include: citizen advocacy, systems advocacy, individual, self, legal advocacy and consumers or peer advocacy, who are free to apply all these modes of action. There is clearly an effective gap in both Australia and New Zealand regarding an independent and systemic consumer advocacy voice that is effective in its representation within government and media.

In spite of this shortcoming, models of patients' rights and the individual rights advocates maintain important core values. There is the maintenance of individual and external independence of thought; transparency of process (although this may clash with working conventions of consumers who are employed within the

service). The transparency of process is central to effective advocacy work. There is the niggling perception from consumer advocates outside of the "system" that "systemic" focused consumer workers may not be acting with urgency or decisiveness in regards to systemic abuses. There is clearly a conflict of interest for those consumer workers "inside" the system. Who can they criticise? Should they dare criticise their own employer?

In spite of these problems, it is evident that "inside" and "outside" consumer workers are necessary to ensure systemic change for the betterment of service users.

Research evidence for effectiveness of consumer run initiatives

Although there are evident problems within the consumer movement there have been a number of developments that are encouraging. In the United States a multi-site research project is underway examining the range of consumer run programmes (COSP). This research is being coordinated by Jean Campbell (1999). The outcomes of this project may inform the sector about the role and effectiveness of consumer peer advocacy and peer support programmes.

Why are we not progressing faster?

It is well established that **empowerment** is an underlying factor in recovery from mental illness (Meagher 1994, and 1995). Yet, after more than one hundred years of mental health patients' rights and consumer rights activity service users are still disenfranchised. Moreover, the general population still perceive mental illness negatively. Mental illness remains as stigmatised today as it was 100 years ago (Clinton, & Olsen, 1998). The Mason Report of New Zealand (Mason, Ken; Johnston June, & Crowe, Jim (1996) noted:

There is no doubt that the feeling of alienation created by stigma is one of the significant reasons cited for loss of hope and relapse by those who experience mental illness. (p 163)

The Australian Burdekin Report made a similar statement. Why is this the case when there has been so much participative activity within the health sector? I would argue our "sector participation" has been too limited. Moreover, I believe our lack of progress relates to the complex issue surrounding identity within mental health services. The irony is our identities are cemented within the illness model by our agreement to work within health and defining ourselves in relation to the service (e.g., service user, consumer and so on). What we need is a wider understanding of "consumer participation" and an agreed "consumer" identity beyond our relationship to service use. It is to this issue that I now turn.

As stated earlier, New Zealand and Australia are western democracies. Surely, within this "free" system of government there is room for the development of greater involvement of consumers. Although most secondary and tertiary mental health services are funded and delivered by government agencies, some services are delivered by NGOs and private businesses. Within this framework there exists an opportunity for greater freedom and the development of significantly different paradigms of thought regarding mental illness and the provision of services. We have already seen how a vibrant arts community can creatively communicate and challenge social norms. Surely such a model can be implemented in other areas (see Appendix 1 for a diagram of the population model).

The limitations of the current system are evident. Much of the development of the Australasian consumer movement has been dependent (or counter-dependent!) on government funded or statutory driven mental health service development and delivery. Not surprisingly, most of the development of mental health services has been limited to government funded agencies and consequently, the consumer movement has followed suit. The history of the consumer movement is a history of engagement with state sector delivered systems. The non-governed or "third sector" health delivery is an area of growing "consumer" participation however, and one that should be encouraged too.

Health sector participation is a movement forward

The problems of the consumer movement are clearly evident but there is evidence that progress is possible. The U & I project in Victoria is a good example. This multi-site study investigated consumer employment. It researched how an acute psychiatric hospital could improve its quality through evaluative feedback from consumers and from staff–consumer collaboration.

Resulting from this work has seen the publication of the "Essential U & I", a one volume edition that details the essential Quality Improvement Systems Model (Wadsworth, Epstein 2001)[1] (See Appendix 3). A fundamental element of this model was the identification of distinct "sites": (i) a decision-making site, (ii) a consumer-only site and (iii) a deep dialogue site. The clarity of the model is useful as it clearly identifies the "context" people work in. Lack of clarity about one's "site" can result in stress. For example, people may think they are collaborating in a "decision making" space when this may not be the case. Conflicts and accusations of tokenism may abound when the cause may be a lack of clarity of one's "site". The "site" may be one of "deep dialogue" instead. The research is detailed and worth investigating further.

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The benefits of hiring consumers

One of the strengths of employing "consumers" to work with the QI systems in the public health service lies in the opportunity for non-tokenistic engagement. There is also the notion of "social role validation", where consumer workers are seen as equal employees and an essential part of the quality improvement team. Problematic is the fact that only a selected few can be employed in such roles. Other "consumers" who are engaging with the service and are not employed by it do not have the same opportunity to achieve this "validation" (Wolfensberger, W. 1991). The optimal effectiveness of consumer advisor employment is dependant upon the whole service quality development being robust as an agreed development, and this is simply not yet the case for mental health services.

There are a range of personal support and development issues to deal with also; some of these conflict with consumer advocacy modes of operating, particularly the degree of the independence of the consumer's voice to the employing organisation (Cartner 2001). By participating within mental health service culture, that culture may become changed towards being more consumer-oriented but often what is not acknowledged is the change concomitantly of the consumer culture through service participation. Consequently, consumers begin to use the language of the professional service (e.g., ethical issues, supervision, safety, and (their own) workforce development) and this language shapes the context of consumer development.

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[1] This is a condensed version of the original publications that detailed the model (Vol. 3)

Clearly consumer-run services is an initiative we'd all like to see more of. They offer "a new vision of healing" and are at the cutting edge of the consumer movement (Fisher, D 1994). In Australasia, we have little support for the development of consumer-run services at present. Yet there is a range of people who use or have used mental health services, have survived the experience and wish to be active to ensure better outcomes.

> *Though they go mad they shall be sane,*
> *Though they sink through the sea they shall rise again*
> *Though loves be lost love shall not;*
> *And death shall have no dominion*
>
> **Dylan Thomas**

3. WHERE ARE WE GOING?

So far I have discussed the history of the consumer movement, problems and developments within it, and research that may lead us towards new initiatives. In this final section I'd like to take account of all these developments and project into the future a possible path for mental health services and the consumer movement.

Paradigm shifts are on the horizon as challenges are beginning to emerge in our understanding of "mental health service". This term is in fact rather contradictory, "mental health service" is less about servicing consumers and more about the business of mental illness (Skynner/Clease 1993). Someone is profiting, and it is not necessarily the consumer. Challenges to the "medical model" and the diagnostic process associated with it are encouraging though. These challenges identify new understandings of mental illness and offer the opportunity for greater benefits to consumers. There is a growing acceptance, for example, that mental well-being is an important component of general health (Ministry of Health July 2001). At the heart of this new understanding is a significant shift in the underlying nature of "mental illness". It clearly identifies a psycho-social causation.

The emergence of this challenge has created solidified positions in both camps. Often, we hear of a clear-cut dualism, the "medical model" versus the "psycho-social model". I do not think the argument can be conceived as simply as this but challenges to the existing mode of thought surrounding mental illness are always welcome. The psycho-social approach at least acknowledges the complexity of mental illness with an inherent understanding of "recovery", which can be defined as "the ability to live well in the presence or absence of symptoms". This understanding forces a shift, "living with" and managing symptoms becomes central as opposed to the elimination of symptoms (Mental Health Commission Blueprint).

This shift in thinking is evident in the mental illness work that focuses on "resilience" and "strengths-based" initiatives. The word resilience originates from the Latin "resilere" meaning, "to jump back". At the core of this understanding is the notion of support of people's strengths and not their weaknesses. People cope through strength and not weakness. There have been attempts to demonstrate these relationships by the design of a "resilience framework" (Karol L. Kampfer 1999), such frameworks may become commonplace in mental health (appendix 2).

As we enter a new century, it is clear that a shift in thinking has occurred. This shift is nicely summarised by
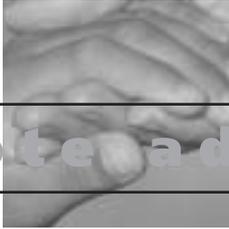
Tessa Thompson (2000) when she writes "work to promote social inclusion is fundamental to recovery ...(it) is not a sideline to mental health services - it is the Heart". If this is representative of the emergent philosophical shift that has occurred, what can we say about ground level initiatives?

I believe a key issue in this area lies in the development of consumer culture finding greater expression outside the mental health sector. So far, much of our effort has been located within participation initiatives in the Public and Mental Health Sector. This is good but hardly satisfactory. There are glaring gaps in our participation within Australasia. This includes: the lack of meaningful political engagement with governments, likewise for new consumer involvement in the NGO sector; the largely unrecognised and unfocused voluntary sector requires engagement around consumer peer support and self help initiatives; and we need more visible representation within business and media. It is evident that "consumer culture" is filtering into the arts sector with movies, literature, visual and performing arts becoming avenues for expression. We do not, however, see people with experience of Mental Illness as opinion leaders or as key dissemination agents leading the recovery philosophy and further articulating human potential for those experiencing mental illness.

In addition to these sector participation issues, there appears to be some key specialist sector themes for development in the near future. These include a clear articulation and expression of effective community care in the ever-present threat of institutionalism. Often the question to be asked is "how can we have community care when the community doesn't know how to care" and also in the face of a strengthening Australasian family movement that sometimes may threaten turning the "care giver" into a "care taker". Honouring "First nations peoples" culture and understandings about health and developing services for and by indigenous peoples is a feature in Australia (Smallwood, White, & Kotiw 1997) and New Zealand (Druie, 1994, 1998) that involves spiritual understanding, holistic context, human rights, and cultural intellectual property. These developments need further expression.

The challenge of creating meaningful Mental Health "Service Quality" systems that are robust "total quality" learning cultures remains on our "wish list" at present. Forced treatment through the administration of compulsory treatment orders remains a perennial ethical and clinical dilemma and the challenge to this practice remains relatively un-coordinated with real and detailed issues yet unresolved. An articulation of "real recovery" has yet to be clarified in Australasia and we have yet to work towards consumers being the acknowledged clinical decision-makers in their treatment. In terms of discrimination and stigma work, the next major breakthrough will be when employees of the health system are able to be open and valued for their own experiences of mental illness. Finally, consumer run business is virtually non-existent in Australasia and there will be developments in this area as there are internationally (The Ontario Council of Alternative Businesses).

Regarding identity, I wonder if the "consumer" movement needs to reclaim stigmatising language. African-Americans have reclaimed the word "black". Why can't words like "mad" and "lunatic" and terms like "mad pride" and "psychotic and proud" be reclaimed for the identity of those of us who experience mental illness?

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CONCLUSION

We shall not cease from exploration,
And at the end of all our exploring
Will be to arrive where we started
And know the place for the first time.

T.S. Eliot, *from Four Quartets*

"Consumer" identity is currently about people who are defined in relation to their mental health service use. In order for significant progress to be made there needs to be a grounded and articulate challenge made to our narrow philosophical understandings. Consumer identity tends to be constructed through the lens of professionalised health services. To resolve this issue we will need Mental Health services working in an authentically public health manner and supporting "consumer" empowerment to encourage partnerships.

Once people with experience of mental illness are visible throughout our communities and are able to participate and contribute across the full range of sectors, effective change may begin to occur.

The challenge for each of us with experience of mental illness is to find a way to contribute that best suits our skills, needs and desires. Many of us will not want our identities to be defined in relation to mental health services anymore. How we begin to question this form of disenfranchisement is key. Perhaps we are due for a revolution as:

Revolutions begin when people who are defined as problems achieve the power to redefine the problem (McKnight 1995, p 16).

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APPENDIX

SECTOR PARTICIPATION DIAGRAM

Fourth Sector: Private (Business) Sector	Third Sector: Non-Government Organised Sector (NGO)	Second sector: Public mental health sector	First sector: Government
			Commonwealth State
	Not for profit sector		
	Voluntary sector		

Arts sector

General population

Media

CARERS "ON FIRE"

Good morning! It's very exciting and a real pleasure to be here with you today. To be able to share with you something that is very close to my heart–and the hearts of everyone involved with ON FIRE! To share with you the exciting work that ON FIRE!, are doing to support, nurture and inspire young people whose parents or siblings have mental health issues. To share with you the story of ON FIRE! , which a growing number of people are saying is a story of hope and possibility, warmth and inspiration … a story of celebration and resilience, of relationship and community. And as such, a story and a glowing symbol for us. For all of us, who know intimately, how mental health issues have shaped and influenced who we are today. For all of us, who share a commitment to take action in forging a positive future together.

Like a spark, ON FIRE! is a small story but all those who know fire, realise how powerful a spark can be. And as my friend Simon reminded me recently, every movement ignited with a spark. Today, in many ways, we celebrate not only our achievements and our aspirations but also we celebrate and acknowledge our young people whose parents or siblings have mental health issues. All 290 000 of these young people under the age of 16, in Australia today. Our precious young people who are finally emerging from the shadows of invisibility. Our precious young people who are a light in the eyes of many of us. And our precious young people who are not just our future but also our present, in every sense of the word.

And what a great place to be sharing this story; in the company of a warm and friendly audience who I have much in common with. I say this because my mother has schizophrenia and also because I have been a young carer. And in this chapter of my life, I am among other things, a mental health nurse.

I feel that the story of ON FIRE! has meaning and importance for you because ultimately, ON FIRE! is about how a bunch of ordinary people, who share a strong common vision, can make a positive and meaningful difference in our community. ON FIRE! is a positive example of standing up and being counted for something that you feel is important–it is about making the choice to be empowered, by putting energy into things we feel passionate and inspired about, looking at that which is possible, building on our strengths, discovering new capacities and abilities, staring with eyes of resilience in the face of challenge, and forging a better future together. It is about resisting the challenge of giving away our energy to frustration, indifference, helplessness, and fear. And while it's not necessarily about doing things on a herculean scale, because perhaps many of us are not in the life situation to do so, but what it is about, is the powerful knowing that what we do, however small, can make a positive and sometimes, crucial difference in the lives of people around us and in our own lives. Small meaningful, sustained grass roots action can serve as a powerful catalyst for positive change on a broader scale. This is why ON FIRE! aspires to create opportunities to fan the "spark " within each of our young people and volunteers, to shine brighter and grow in radiance.

Before going on to share with you the type of work that ON FIRE! are doing with young people whose parents or siblings have mental health issues, I'll share with you a little bit about my own growing up experiences. I think this will give you a better idea about the inspiration for ON FIRE! and why ON FIRE!'s approach to working with young people takes a strength based and peer support focus, rather than a deficit or problem focused perspective.
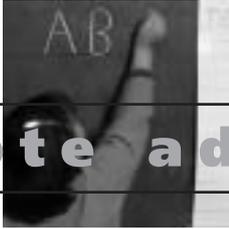
When I was about 15 years old, mum gave birth to my brother Steven. Steven didn't belong to my father - so shortly afterwards, mum moved out of home and separated from dad. She took Steven with her. In the months following this, mum wasn't quite the same - often she was very tearful, very sad, she slept a lot, and among other things, was more irritable than usual. She lost a lot of weight and she lived in between inner-city hotels and my aunt's place. She was having trouble coping and in the end, Steven was removed from her care and placed in foster care. This was utterly devastating for mum, because so much of who she was, was about her being a mother.

At the time, my sister was about 10 years old and my brother was about 8 years old. In the months that followed, mum was eventually accepted back home and as time went by, she began to develop the first signs and symptoms of schizophrenia. But of course at the time no one in our family knew anything about mental illness. Mum's self-care deteriorated, she started smiling and laughing for no apparent reason, she became vague and disorganised, and she started to talk about grandiose and paranoid themes. She would stay up till the early hours of the morning talking and sometimes shouting to herself. Her reality was no longer one that we shared. Mum was very unwell for about 5 years and in this time it seemed as though we could barely relate to her, despite the fact that she was our beloved mother. Perhaps the greatest wound was that we no longer enjoyed the very close relationship with mum, which we once did.

As you might suspect, our whole family descended into a world of madness, a descent which spawned many silent tears within the hearts of each of us–silent tears because we didn't know what was going on with mum, or ourselves. Silent tears because of the stigma and ignorance that abounds in our society towards those who are considered "different". And as many of you know, a silence that is sometimes deafening. At times, such as at anniversaries and when conflicts flared up, the hurt that our family experienced was sharp, intense and profound—at other times, it was subtle—like in those moments of calm and aloneness when you realise the loss and grief, the brokenness and woundedness that have been uninvited into your life. Those moments when you try to make greater sense of the dark clouds of confusion and chaos that fill your atmosphere.

As a young person it was disturbing watching my family fall apart; family which had once been a place of nurturance and protection, was now a place of chaos, fracture, and unpredictability. I remember watching and experiencing with young eyes, things that made me older than my years such as seeing the brokenness of heart that mum experienced as a result of the removal of Steven from her care.

They say the eyes are windows to our souls, if we take the time to look into them. As a young person, I gazed into the eyes of my family. I remember the torment in the eyes of mum, the helplessness and frustration in the eyes of dad, the confusion and sadness in the eyes of my brother and sister, and the hurt and sorrow in my own eyes. No longer clothed in the relative innocence of youth, I felt at times, a sense of being alone and vulnerable in a world that had once nurtured me, but a world that now confronted me with a harshness of realities and an intensity of feelings that I had not known before. In a way, so much of my innocence and youthful naiveté had been wrenched away from me. In its place, came a powerful cocktail of strong and at times, conflicting feelings, such as hurt, confusion about what mum's illness meant to our family, resentment about why had this

happened to our family? , guilt about what more could I have done to prevent mum from becoming unwell? , sadness which speaks for itself, and above all, loss. Loss of the mother that I had once knew. Loss of the sense of family that I once enjoyed. And the loss of all those things that remain unspoken.

And, while some of the experiences that I have shared with you were difficult times in my life, this represents only part of my story. You see, much goodness has emerged from those heavy-hearted days. Like fresh rays of sunlight that pierce once-heavy clouds. Or, as the Chinese say, the second face of crisis is opportunity. I like this saying. Maybe that's the Chinese in me.

Clearly, my growing up experiences have fundamentally helped shaped who I am today and the work that I do with ON FIRE! I am proud of who I am, and proud of who my mother is. She is much better these days, quite a character actually and I love her so much just the way she is. One of the most incredible things is the sense of unconditional love that I feel exists between mum and I. We share a strong relationship that celebrates a groundedness and simplicity that has emerged from a journey that we have taken together. These things serve as a compass of love and a shining source of inspiration, wonder and beauty for me. When I pause to reflect on this I still marvel at the gift this is, in my life, what this means to me, and what this suggests about the transformative power of love.

The colourful journey that has been my life so far, has revealed to me the fragility of the human condition and the tremendous resilience of the human spirit. Our deep yearning to experience love: to love and to be loved. Beyond this, our capacity to make sense of that which makes no apparent sense, our capacity to discover those moments of peace that dwell deep within us, our capacity to trust enough to enjoy the intimacy of connecting with and relating to people around us, our ability to stare at life with eyes afresh with eyes that gently invite us to dare to hope and dream once again, to seek joy and pleasure in those small and inconspicuous moments such as shared smiles, gentle encounters and fond memories, … to be crazy enough to really accept into our lives the richness and complexity of life that has been part of humanity since time eternal.

When I look back at my growing up experiences, I see the gift of a beautiful rose. A rose that has been adorned with thorns–thorns that I have previously mentioned, and a rose that is also adorned with rich, vibrant petals. A radiant, precious rose which is a source of beauty and inspiration. A rose that has made me a more loving, gentle and compassionate person and a person who has a deep-seated conviction, a fire, to make a positive contribution in our society. And one of the most magical things that I learnt as a result of my growing up experiences, was the ability of one person to make a positive difference in the life of another. And the intuitive knowing that there is perhaps nothing more important in life than the experience of relationship

So what a joy it is to be part of all that ON FIRE! represents, all that ON FIRE! is and all that ON FIRE! can be. To be part of something, in it's own small and meaningful way, which is gently helping to create a more loving and joyful world.

I sense that many of you are able to relate to some of the things that I have chosen to share with you about my growing up experiences. I have shared these experiences for a number of reasons. While of course my experiences certainly do not reflect all of the experiences of the 290 000 young people whose parents alone

have mental health issues, there are aspects of my story that I hope have deepened your understanding of some of the experiences and needs of our young people. I also hope that it has helped illustrate that while many of our young people do experience challenging life experiences, with support and favourable life situations, young people do have the capacity to grow in strength, develop resilience, and forge a bright future. It was from this awareness that the spark for ON FIRE! was created.

I think it's important to briefly paint a picture of how the spark for ON FIRE! evolved into action; for every group has a beginning and there may well be groups as yet unformed in the audience. Earlier this year, I joined a group of friends up at Woodford Folk Festival. While having a fun-filled time, and over a cup of chai tea or a pint or so of Guinness, we asked ourselves the question of where we wanted to focus some of our energy this year. We discussed our commitment to making a positive difference in our community and our passion for working with young people, and our belief in the importance of small grass roots action and how this can serve as a catalyst for good work on a broader scale. After a while we came up with the idea of doing a range of direct initiatives, such as leisure and peer support activities to support young people whose parents or siblings have mental health issues.

We chose this group of young people because of our own life experiences and our understanding of the adversity these young people sometimes with. Not only this, but we believe that these precious young people, often have so much to offer the world through their compassion and sensitivity, the wisdom of their lived experience, and their inspirational capacity for resilience. So we looked at what was currently out there to support these young people and came to the conclusion, that while it is promising that there is a greater awareness of the value of supporting these young people, and that government has begun to address some of the needs of these young people, ON FIRE! had a valuable contribution to make in complementing the existing work especially because a lot of this existing support is currently focussed at a more systemic level (though there are notable exceptions such as the excellent work being by Leigh Cowley and his Gaining Ground team in South West Sydney). It's also important to note that some area health services are at quite an early stage of development in terms of supporting these young people. So in creating ON FIRE! , we decided that we would focus on doing small meaningful initiatives that would directly support the young people we come into contact with. Some would say that direct support is too time intensive or too resource inefficient. Some would say that direct support is like putting bandaids on people. ON FIRE! believes that a bandaid sometimes prevent an infection. And while bandaids don't always take pain away, when given with warmth and concern, bandaids always show the precious individual, that someone cares. This knowing can do powerful things in people's lives. That is why I believe, in order to effect positive change, systemic and direct initiatives are each important. At ON FIRE!, we hope that the work we do will serve not only to make a positive difference in the lives of the young people we come into contact with but also to act as a catalyst for other people and groups to get together to support young people in their local regions. That's why we are very open to forming collaborative partnerships and sharing our knowledge, skills and experiences with interested others.

So by early this year, we formed ON FIRE! We developed a Vision Statement and Strategic Plan, put it out to a number of different people and the responses we received were filled with positivity and enthusiasm. And as

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such, more people decided to come on board and work together to support, nurture and inspire young people whose parents or siblings have mental health issues.

In our aim to promote the mental health and wellbeing of young people, we decided that our approach to working with young people would take a strength-based, peer support focus. The way we go about doing this is by organising activities and relating to young people in such a way that builds on their strengths, recognises their resilience and encourages possibilities in their lives. We do this ever so gently and in a manner that respects where young people are up to in their lives. This also means that we certainly do not romanticise, minimise or trivialise their life experiences or the challenges present in their lives. This enables young people, over time, to discover, recognise and celebrate their resilience.

So you see, ON FIRE! does not operate on a "problem " or deficit model. We do not have pity for our young people. We have hope for them. We do not seek that which is wrong in them but instead that which strong in them. We are not experts in their lives, we are merely present in their lives as they come to better understand themselves and the world around them. We are not like sages on stages, but rather, like the guides on the sides. ON FIRE! activities are not clinical or big "T" therapeutic in nature. We appreciate that there are other organisations that provide young people with those important forms of support. In this way, what we do is in resonance with a peer support approach where young people learn from each other and learn more about their own experiences and abilities in the process. So this is what we mean by a strength-based, peer support approach.

It's now time to talk more specifically about the work that ON FIRE! does. ON FIRE! works in collaboration with a variety of people and organisations to provide a range of peer support and leisure activities for young people whose parents or siblings have mental health issues. The interests of our young people and the knowledge, skills and abilities of our volunteers ultimately determine these leisure and peer support activities.

Before telling you more about some of these exciting initiatives, I think it's worthwhile making a few comments about our strategy for engaging young people. Perhaps you will find useful, some of what I have to say. Our understanding is that if you want to engage young people you need to listen to them and offer them something that they see as meaningful and relevant. So giving someone bananas, when someone asked for sunscreen doesn't make much sense! So engaging young people means being attentive, flexible and innovative. It means being eagerly prepared to see things through their eyes, and enabling young people to be co-authors of the vision and initiatives that we are partners in. Otherwise, young people might not turn up! And there is the chance that we could fall into the trap of thinking that young people aren't out there or that they don't want any form of support–young people whose parents or siblings have mental health issues are out there, more than 290,000 of them! And just because they don't necessarily ask for the support that we perceive is important for them, doesn't mean that they don't want support that is on their terms.

Now for most young people, at the outset, the chance to have fun is one of the things that has most immediate meaning. From our experience, camp equals fun. Other stuff might not be as cool. But as time goes by, other things do become fun and meaningful as well. Things like being able to talk about stuff that happens at school

and at home with someone who is non judgemental, someone who listens and cares. Being able to express feelings in a safe and supportive environment. Being able to learn better ways of dealing with tough stuff. Being able to hang out with a bunch of other young people who know what it's like. Being able to be encouraged by a group of warm-hearted volunteers who have seen a bit of life. Some of these volunteers have even grown up with parents or siblings who have mental health issues themselves. Being able to feel a sense of acceptance, connection, relationship and belonging.

Now camp is a great example of this. So often young people and their parents and carers understand that camp is a place to have a fun, safe and meaningful experience. Camp is a chance to make friends, feel supported and build on existing life skills. Invariably, young people have such a great time and enjoy activities like the Peer Support Chat Groups and the Creative Expression Groups, that once camp is over, they are keen to become involved in other ON FIRE! initiatives such as Telephone Group Chats, Fun Day Outings, Life Skills Workshops, Mental Health Education Workshops, Creative Expression Outings, Adventure Activities and so on.

So in many ways, camp is like a springboard from which young people leap into other initiatives. Initiatives that young people may otherwise have been reluctant to be involved in before experiencing camp. This is why camps are currently the flagship of the work that ON FIRE! is involved in.

Having started to recognise the importance of camps, let's now focus our attention on Camp Tuncurry, which in many ways represents so much of what ON FIRE! is about. In July this year, ON FIRE! had the pleasure of supporting Camp Tuncurry by providing volunteer camp leaders. Camp Tuncurry is a wonderful initiative of the Rotary Club of Great Lakes Inc., for young people whose parents or siblings have mental health issues. Harold and Barbara Rowe are the driving forces behind this exciting initiative.

Now I think Camp Tuncurry is fantastic because Camp Tuncurry is a wonderful example of how people can come together to do something that is really special. And that something special is the opportunity for young people to have a fun-packed week, in a warm and caring environment that helps bring out the best in our young people. All up this year, we had more than 100 volunteers involved with the camp! Camp Tuncurry takes place at Shangri-La Village, Tuncurry. The residents of the Village have a social club of mostly retirees who get together to do various activities throughout the year. The biggest of their activities is their preparations for Camp Tuncurry. Organising the meals, cleaning the cabins, decorating the hall for special presentations, organising showbags for the campers, sharing a welcome smile, giving a bit of encouragement to the young people and the leaders, and being those important people behind the scenes who you can rely on to help make camp the fantastic experience it is. Like our ON FIRE! volunteers, those residents and all the Rotarians, Lion's Club, and Quota Club volunteers, as well as the many other people from the Forster-Tuncurry community, put a lot of heart and soul into what they do. I think that's what makes Camp Tuncurry so special. Our young people experience so much generosity, warmth, gentleness and encouragement that they are sometimes surprised by it all. One young camper asked me at camp earlier this year, why are people so kind at camp? In a sense, Camp Tuncurry is like the TV series "Seachange", meeting the movie, "Cocoon"! Some of those older folk sure know how to make people feel welcome. I think that there is something special in seeing our young people relate to people

who have seen so much of life. It is such a positive experience seeing the generation gap between young and old being melted away by the mutual respect and affection that they end up sharing by week's end. Those volunteers reaching out with their kindness, while the young impress with their charm and the poignancy of their stories. All the while, having a bunch of ON FIRE! volunteers—young and not so young—being in the midst of all the excitement and mayhem of camp. Just talking about camp makes me feel once again, the warmth and joy of camp in my heart.

While being part of camp for 5 days with more than thirty excited young people certainly has its challenges, there are so many moments that reveal camp to be the special place it is. Like when a young person looks you in the eye and says to you that before coming to camp they have never met any other young people who really understand their experiences. Like when a young person begins to share with you how very much they love their dear mother or father, brother or sister who has mental health issues. Like the sacredness of when young people begin to share their story for the first time, with other young people who know what it's like and who know how to convey the warmth, empathy and that can only come from shared experience. Like when a young person tells you that camp has helped them feel better about themselves and better able to handle the challenges that face them in their daily lives. Like when young people become confidant and trusting enough gets to ask questions that for so long they have been afraid to ask or who have not known who to ask. Questions like, "why does dad do the things he does"? "Did I cause mum's illness"? "Will I get sick as well"? "How did you get through tough times"?

I can't begin to tell you how beautiful it is to see some of the young people leaving camp with hearts no longer as heavy with sadness, confusion and frustration. And instead leaving with greater hope and confidence, more peace and acceptance, and a deeper understanding and appreciation of how much they love their family member who has mental health issues. So often I hear young people tell me in their own way that because of camp, something has shifted in their lives. Something about their life is better; something that is difficult to articulate. And these things don't just happen in the lives of our young people but also in the lives of our volunteers. For instance, some of the Tuncurry volunteers have said to me that they have as much fun as the campers–they say camp is a focal point that brings their community even closer together. Camp is an opportunity where they get to do little things that make a difference in the lives of others. Like the milkman who donates fresh orange juice every morning. Like the lady who prints off beautiful documents which bear the meaning of the names of the young people. Like the local photo development business that processes the photos. Like the local archery club who let us use their clubhouse and who teach us how to do archery. And like the really old lady, who donated a massive bag of mandarins because "I've heard about the good work that you do". Each of these people doing their little bit, all adds up to making a big difference. It's one of the things that makes me proud to be an Australian; the fine volunteer spirit that exists in our community. So you see, at camp we all learn about ourselves and each other–we let our light shine. The warmth, nurturance and acceptance that the community of young people and volunteers share for a week, is truly something that is a privilege to be part of and something that we each take away from camp and place in our hearts.

Many people have said that Camp Tuncurry is a wonderful example of communities coming together to do great

work. An example of the good that can be achieved when people join with open hearts and a strong common vision to make a positive difference in the lives of others. And it's not just the young people and volunteers who talk about how important camp is. Parents and carers have been generous in their praise as well. Here's what some of them have had to say about their children and camp in general:

"[she] could not stop talking about it for weeks."

"[he] came home a more relaxed, happy kid. Communication between him and I has improved."

"Being [his] sole guardian, it allows me to have some time to reassess where I can help us relate to one another."

"It's important for him to share his experiences and gain a sense of where his situation fits in the continuum of experiences."

"[we] are very close, I feel that it was a fantastic experience [for her] to be able to express herself and know there are other children who have parents with a mental disability."

"[he] loved to be with other people his age group and to be able to talk and share his ideas."

"[he] has matured a great deal more since camp … Camp enabled him to discuss issues he needs to that he sometimes finds hard with me."

"[he] came back a different little boy … he is coping a lot better since the camp then beforehand. Thank you very much.."

"I feel that she listens to me more than before. She seems [more grown up]"

"we have become much closer. [He] is more understanding and a whole lot more patient in general."

"He has been more loving … full of loving remarks and appreciative."

"He is more understanding of the issue at hand … he is more loving and patient and he can express his feelings a lot better."

"[she] seems more mature and seems to look at the world in a slightly better way."

"[he] expresses himself a lot better [and] understands the issue of depression now. He is a lot more loving and patient."

"… we are very close but I feel we are even closer."

"[camp gave her] the experience to do new things and to learn from other kids and from [Peer Support] Chat Groups."

"Interacting with his peers made a vast improvement in his way of dealing with certain issues."

"[she] has always been a very responsible, loving and very caring child, but I think she gained a better insight into my illness."

"I believe the whole experience was very beneficial to [her], as she was reluctant to ever be away from me, now she can't wait for the next one."

"You all did a great job with our children. Thank you."

"Camp is a fantastic organisation for young people to help them to have fun. We really appreciate it."

"I'm sorry but I truly believe you all do an incredible and very special thing with each and every child. I thank God for people like you that are so dedicated."

As you can gauge from these very positive comments, camp is indeed a special experience for so many of the

young people who have the opportunity to be part of it. Actually, when we asked young people what could be improved about camp, they overwhelmingly said to make it longer than a week. Now I'm not too sure if that would a good thing for the mental health and wellbeing of our volunteer camp leaders!

But the message that we took away was that they wanted more contact with each other. That's why we decided to start having Fun Day Outings every six or so weeks. For these Fun Day Outings, we get our young people to nominate places they consider fun and then we go about organising outings to these places. This regular contact is great because the young people get to build their friendships with each other and they have a regular opportunity to get things off their chest if they want to. For us volunteers, its very rewarding getting to better know our young people and watching them grow and blossom. On our first Fun Day Outing this year, we were let loose on Jamberoo Recreation Park where we sped down bobsleds, raced go-karts, rode chair lifts high into the sky (taking in breath taking views of Jamberoo Valley), slid down icy cold water slides and even played putt-putt golf. We enjoyed having a tasty meal together and having time to catch up with each other sharing stories, laughs and a sense of excitement and joy. On our second Fun Day Outing, we had another excellent day at Taronga Park Zoo where we enjoyed the lovely weather and took in the beautiful harbour views. We made funny faces and noises at the animals and the animals made funny faces and noises at us. We even went for a short bushwalk and swim on a little beach. Next weekend, we are gearing up to do part of the Spit Bridge to Manly coastal bushwalk, which will be followed by cooling down at the Manly Waterslides before staying overnight with the creatures from the deep, at Oceanworld Manly. Once there, we'll be enjoying a BBQ, video, aquarium by torchlight walk, a Peer Support Chat Group and a long night at a pretty big fish tank!

A couple of months ago, ON FIRE! also facilitated a Telephone Chat Group for some of our young people. This was like having a Peer Support Chat Group, but over the phone. It was a really good way for some of our young people to keep talking together about different themes and issues that were brought up at camp. Things like talking about how they feel about having a parent with mental health issues. Talking about some of the things they worry about. Talking about some of their hopes and dreams, and talking about how important it is for them to know other young people whose parents have mental health issues. Each of the young people said they found the Telephone Group Chat was something that they really enjoyed and something that they felt was worthwhile being part of. I think it is a particularly good initiative for any group of people who are geographically or socially isolated. Carers NSW have been one of the pioneers in this field so keep them in mind if you are interested in finding out more about the Telephone Group medium.

We have also been putting out the FIRESIDE Newsletter, which we send out about every 8 weeks. Often this is a good place for our young people to keep up to date with our ON FIRE! activities and another way of feeling connected to their group of peers. So you can see ON FIRE! have been putting their vision into action and having a ball doing so!

ON FIRE! is also very excited about a number of new initiatives that will be developed for next year and beyond. I'll briefly paint a picture of some of the directions that we are heading. There might be something that relates to you or something that you might be interested in finding out more about. At ON FIRE! we have started
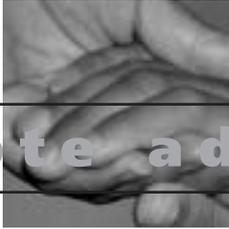
to hear that our young people are interested in a range of other initiatives. They are interested in Life Skills Workshops such as learning how to relax, and how to develop better coping strategies. Several of our young people have expressed an interest in learning more about mental health and we are also exploring the idea of getting a group of young people together to help create a publication that helps other young people whose parents or siblings have mental health issues. Some of our young people and volunteers are very creative, so we are planning to foster this talent by organising some Creative Expression Outings and workshops. A theme for some of our older members is that they would like to do some overnight camping in the bush and other adventure activities. In the years ahead, we are also keen on organising a coaching program and leadership development program for our older members. I think these programs have a tremendous amount of potential and no doubt, some of our young people may become volunteers themselves thereby helping to ensure the sustainability of the valuable work that ON FIRE! are doing. ON FIRE! and all those who are involved with ON FIRE! are certainly involved in a range of very exciting activities and many more are on the horizon.

Having heard about some of the initiatives that ON FIRE! are involved with and some of the exciting directions that ON FIRE! are heading, you can see that the ON FIRE! story started with a spark and is now alight, touching the lives of a number of people. I believe that over time, in its own small but meaningful way, it will touch the lives of many more people. Who knows, in some way it might just become part of your own story?

It's time now to begin to draw together some of the key themes that we have shared together today. The ON FIRE! story is really about warm-hearted volunteers who feel passionate about supporting, nurturing, and inspiring young people whose parents or siblings have mental health issues. And we do this through small and meaningful actions. Actions that say to young people: we are gently present to respectfully listen and affirm you for the person you are. We have confidence in you and believe in your ability to grow in resilience. We care about you and are cheering for you. You count. You are precious. And you are not alone.

Our ON FIRE! activities, create a space where young people with similar life experiences can come together in a positive and encouraging environment where they feel safe and valued enough to share their stories, where they come to express their feelings and try to make sense of their life experiences, where they come together to relate to other young people, where they have an informal opportunity to learn from each other, where they come to a place of support and nurturance, a place of sanctuary, a place of hope and possibility, a place of building on existing strengths and discovering new abilities, a place to have fun, test the limits, step out of their comfort zones, come to celebrate their strengths and joys, and ultimately to express who they are and where they are at in their own life.

Young people whose parents or siblings have mental health issues. These same young people who have so often been hidden, and sometimes doing it tough. These same young people who are in your local community, your local schools, who are quite possibly in the street that you live in, and maybe even the person sitting next to you grew up with a parent or sibling who experienced mental health issues. Our young people who are not just part of the future we wish to forge, but also our present, in every sense of the word.

Imagine what ON FIRE! means to you?

Perhaps there are young people you know who might benefit from becoming involved in ON FIRE! activities? Perhaps you could help raise the awareness about ON FIRE! activities among your friends, colleagues and networks? Perhaps you know of funding and in-kind support opportunities for ON FIRE! ? Perhaps you know of organisations that may be interested in auspicing ON FIRE! initiatives? Perhaps you know of some people who are potential volunteers for ON FIRE! activities? And finally, perhaps ON FIRE! is in some way a spark, a glowing symbol of the good that can emerge when a small group of dedicated people, who share a strong common vision, come together to make a positive difference in the lives of others.

I'd like to finish with a little story.

At Camp Tuncurry this year, we had a shy, nervous little boy called Joe* who was about 10 years old. Joe had been to Camp Tuncurry last year as well. And all of camp last year, I remember him rarely venturing out of his shell. Rarely would he say anything. Rarely would he make eye contact and rarely would he take off his big George Castanza jacket or his big, brown floppy hat that would shield his face away from the eyes of others. Even this year, he wore that big jacket and big, brown floppy hat. But something was different about Joe this year. This year he seemed more relaxed and more confident. He seemed to smile more and on a couple of occasions he even started up a conversation with me. Apparently he likes drawing and he tells me the food at camp is good. But by the second last day of camp, something unusual happened while we were at tenpin bowling, I saw little Joe without his big jacket and big, brown, floppy hat. And yes, he did have hair on his head and yes he did have pretty fair skin but he was also being more animated and more playful than I've ever seen him before! Shooting off smiles that would split a melon, giving his peers high fives and cheeky comments. I thought it was great seeing this young person coming to life. And yet about an hour later, one of the leaders, Julieanne, came up to me and told me that Joe had been crying. I didn't know what to make of it. I thought that he had been having fun at camp. When I got to the bottom of it, this is what had happened. After Ten Pin Bowling, we were all going to the indoor aquatic centre for a swim. And some how, Joe had kept the plastic swimming wrist band from last year, and this wristband had somehow broken while he was at Ten Pin Bowling. When Julieanne asked Joe why he was so upset, Joe said to Julieanne that he had worn last year's plastic swimming wrist band every day for an entire year! And why? because "it helps me remember my time at camp". Now it goes without saying, Joe was not the only one with tears in his eyes except I'm not sure if they were tears of sadness or tears of joy. But what I can tell you is that we made sure Joe got a brand new plastic swimming wristband this year!

Thank you for being such a warm and interested audience. Have a wonderful conference, I hope you gain strength and draw inspiration from each other so that you can each return to the places where you make a positive and meaningful difference in your own way. And finally, isn't it great to actually make the space and focus our attention on acknowledging the importance of celebrating each others stories of hope, resilience and human spirit–especially when our experience of humanity can sometimes be skewed by focussing on our fears, frustrations and uncertainties. A rose is adorned with thorns and petals. But if we gaze only at the thorns, then surely we miss the fullness of the rose and in doing so, the fullness of our human experience.

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Professor Beverley Raphael, Director of the NSW Centre for Mental Health officially unveiled the National Standards Quilt, during the first day of this conference. Professor Raphael complimented CAG and everyone connected with the project on the outstanding representation of the national standards and the quality and skill of the finished work.

The National Standards Quilt Project came from an idea of Ms Mary Beth Allen during the planning for the National Standards Festival held on 7th October, 2000. The National Standards Festival Committee convened by the NSW Consumer Advisory Group thought that a quilt could be a discussion point and a way of educating consumers, carers and service providers about the National Standards for Mental Health Services. Mary Beth developed the centre-piece which was displayed at the Festival. A list was compiled, distributed and some squares were chosen by groups and individuals from all over NSW. The original plan consisted of 18 quilt squares.

By June 2001 most of the squares were still sitting in sewing baskets, but members of the NSW CAG began a push to have the Quilt completed for the Forging Our Future II Forum on the 9th and 10th of November 2001. Joan Wakeford became coordinator with Desley Casey, and as Tamworth has a thriving fibre-craft network the remaining standards were placed there. And suddenly the Quilt comprised all of the Standards and became a set of panels! The assembling was completed by Prue Campese who did all the machine sewing, while the stories about each square were being collected and written down.

The creative way that people have depicted the National Standards is testament to the regard consumers, carers and service providers have for them. Many of the people sewing the squares had very stressful events occurring in 2001 (including the coordinators!) yet the quilt project brought people together in very supportive ways. Tears were often shed over these squares as stories were shared. Yet the most used word on them is "hope". Over one hundred people contributed to the planning and making of this Quilt. Your stories are beyond measure.

Delegates were invited to share their stories on how they perceived the quilted National Standards and to write their comments in the book that will travel with the quilt. The organisers hope the Quilt will make a difference and lives will continue to be enriched by the impact of this beautiful work.

The quilt is in three panels. Panel one features Standards 1–10. The other two panels include the centrepiece and the many facets of Standard 11.

The purpose of the quilt is to inform and educate everyone, the community, consumers, carers and service providers on the National Standards for Mental Health Services in a creative way.

NSW CAG hope this quilt will promote awareness and discussion of the National Standards for Mental Health Services. The quilt will be available to come to your area as a tool for discussing how a specific National Standard can be implemented within your mental health service.

Our thanks are extended to consumers, carers and service providers throughout NSW who have played a part in the creation and development of the quilt.

keynodancedress

Choreographer:Lisa Cutler

This contemporary dance piece was choreographed to explore understandings and attitudes about mental illness, and leads us towards thinking about hope and possibilities.

Lisa Cutler is an experienced dancer and choreographer who is currently working at Richmond Fellowship. She researched the dance through interpreting the voices of those she interviewed for the piece. By deconstructing many individuals' experiences with the so called mental health system and their illnesses, Lisa crafted a path of discovery with the dance troupe, and for the audience.

Six dancers took to the stage guiding us towards different thinking about mental illness and working towards challenging negative attitudes. This was no easy task, but it was an interesting way to think about promoting positive mental health. The dance troupe comprised consumers, carers and health professionals.

The dance invoked a range of emotions and would challenge any audience to think about mental illness in a challenging way.

session 1 consumer groups in area mental health services

1.1 Northern Sydney Mental Health Consumer Network

Desley Casey

The Northern Sydney Mental Health Consumer Network is a network of consumers whose primary function is to encourage and pay consumers to participate at all levels of the mental health services. To help with these functions five local networks have been established at Hornsby, Lower North Shore, Macquarie Hospital, Northern Beaches and Ryde.

The Consumer Network operates from a set of guidelines written by consumers. A Code of Conduct also assists consumers in their various roles of consumer participation. There are approximately 150–200 consumers involved at some level with the consumer network in Northern Sydney. We look forward to increasing our membership to give as many consumers as possible the opportunity to participate in ways they feel they can.

1.2 Consumer Participation in Central Sydney

Peter Schaecken

An innovative programme for mental health consumers has been developed within Central Sydney. For too long people who live with a mental illness did not have a voice, were not viewed to be competent to make decisions about their treatment, and experienced stigma and discrimination in the communities they lived in. Within the framework of the National Mental Health Strategy beginning in 1993, Central Sydney mental health consumers have been given an opportunity to turn around some of these issues with the development of a comprehensive programme involving partnership with Central Sydney Area Health Service.

In 1994 a Consumer Consultant's service was established in Rozelle Hospital which was unique in that people with a mental illness were employed to provide a peer counselling service. This was one of the first services of its kind in Australia. Helen Blum has been consumer coordinator since the programme's inception to the present day and is responsible for 6 consumer consultants. Consumer consultants have received initial training and ongoing support and are able to assist mental health consumers through shared experiences, providing information about rights and acting as advocates if requested. As a result of the Rozelle Hospital "consumer consultants" similar projects are happening all around Australia.

In early 1996 the position of Area Coordinator of Consumer Initiatives was created. This role includes developing Area Consumer Initiatives, coordinating and supporting consumer participation and consumer representatives and education activities for consumers.

The achievements of the consumer initiatives programme were recently recognised at The Mental Health Services Conference of Australia and New Zealand 1998 held in Tasmania where the Rozelle Hospital Consumer Consultants received an award for their achievements. Likewise Mr Peter Schaecken and Ms Liz Deacon received the Ray Brown Award for their excellent paper on Consumer Initiatives at the Rozelle Hospital Winter Symposium 1998.

Strategic plan for the development of Area consumer initiatives and consumer participation policy

In 1996 an Area wide Consumer Initiatives committee including staff and consumer representatives from each Sector Community Service and each of the 3 Inpatient facilities in Central Sydney began meeting.

By the end of 1996 A Consumer Participation Policy and a Strategic plan for the Development of Area Consumer Initiatives had been developed and approved by the Area Mental Health Clinical Council.

The five target areas are:

1. Consultation processes

Objective: Wide consultation with consumers to ensure consumers have the opportunity to influence decision making processes at an individual and organisational level

2. Peer support services

Objective: The establishment of peer support services which employ consumers with mechanisms to develop and ensure an integrated service

3. Participation policy

Objective: The development of an Area Consumer Participation Policy

This policy looks at the barriers to consumer participation and gives strategies to address these issues. It explores the issues for gay and lesbian consumers, Aboriginal and Torres Strait Islander consumers and people from a non English-speaking background. It also covers issues such as who selects consumer representatives.

4. Staff and consumer collaboration

Objective: The development of a collaborative and participative culture in the Area Mental Health Service

5. Consumer employment

Objective: The development of an area programme for consumer employment

Through the Plan, the Area is moving towards having consumer representation on most non-clinical committees. e.g.

      i Area and Sector Quality Activities Committees
      ii Area Mental Health Clinical Council
      iii Monthly Staff meetings
      iv Community Consultative Committees
      v Patient Care and Consumer Care Committees

The Area Mental Health Service includes consumers in Educational Activities including:

      i Understanding mental illness workshops
      ii Aggression management workshops
      iii Early intervention training programme
      iv Individual service Plans training
      v Suicide awareness workshops
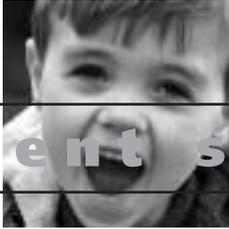
Support for consumers and consumer representatives

  i Consumer forums are held biannually

  ii Consumer representative training programmes

  iii THEMHS conference attendance

  iv Currently in the early stages of establishing a consumer network

  v A public speaking course for consumers

  vi Community consultative committees

Some of the achievements of consumer initiatives and community consultative committees

Community consultative committees offer members the opportunity to raise issues of concern and share information. Some of the achievements have included:

  i The development of the "Working with your Service Coordinator" brochure

  ii Currently developing an "Acute Care" brochure

  iii Plain English version of "Your Rights as a Consumer" brochure, and

  iv The establishment of the "Double Trouble" support group for mental health consumers who use alcohol or drugs.

Expected outcomes from consumer participation

  • a better understanding for consumers of the structures of the Area Health Service;

  • an easier mechanism to make complaints;

  • feedback from consumers which may not have otherwise been received;

  • a change of culture;

  • a better service more responsive to consumer needs;

  • more working together rather than us and them;

  • a move towards the greater empowerment of consumers;

  • better outcomes for consumers;

  • improved consumer satisfaction.

For more information please call Peter Schaecken 02 9564 2122.

1.3 Western Sydney Mental Health Service Consumer Network

Jodie Brown

Area Profile

Western Sydney Area Mental Health Service (WSAMHS) is one of seventeen area health services in New South Wales, Australia and is located the western suburbs of Sydney. Data from the 1996 census indicates that the population of the area is 645,390[3]. The region is also characterised by large areas of socio-economic disadvantage as well as over 30% of residents reporting that they speak a language other than English at home. Highly represented in these language groups are people from Arabic, Chinese and Philippino/ Tagalog backgrounds. The area also has a large indigenous community (12.4%).

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[3] This figure is projected to increase to 682,300 by the year 2001 (a Profile, WSAMHS, 2000).

Western Sydney Area Mental Health Service

The Western Sydney Area Health Service (WSAHS) takes in 5 local government areas including Parramatta, Auburn, Holroyd, Blacktown and Baulkham Hills. It has 2 sectors: Greater Parramatta Mental Health Service and Blacktown City Mental Health Service.

Across the area there are 419 beds (inpatient=306, community=113) which are spread across the following units and programs:

- 5 acute units;
- 1 aged care unit;
- 1 CADE unit;
- 1 forensic unit;
- 3 residential programs;
- 5 rehabilitation units;
- 8 community health centres;
- 1child and adolescent unit;
- 1 early intervention team;
- 1 prevention, promotion and early Intervention program; and,

As well as partnerships with:

- 3 social/recreational programs;
- 2 vocational programs;
- 2 non government organisations.

Western Sydney Area Mental Health Services

The Consumer Network

Initially a sector based program that was developed into an area program in 1999. The program is staffed by a full time Consumer Network Coordinator, a Senior Consumer Consultant and nine Consumer Consultants. All consumer network staff are full employees of the area health service. They work from 3 hours to 40 hours per week and report to the Consumer Network Coordinator.

Organisational Chart

Area Director, Mental Health WSAMHS

Director Operations and Strategy
(Deputy Director)

Director of Nursing, Director Community Services East and West

Consumer Network Coordinator

Senior Consumer Consultant

Reporting lines + ————————

Communication lines - - - - - - - -
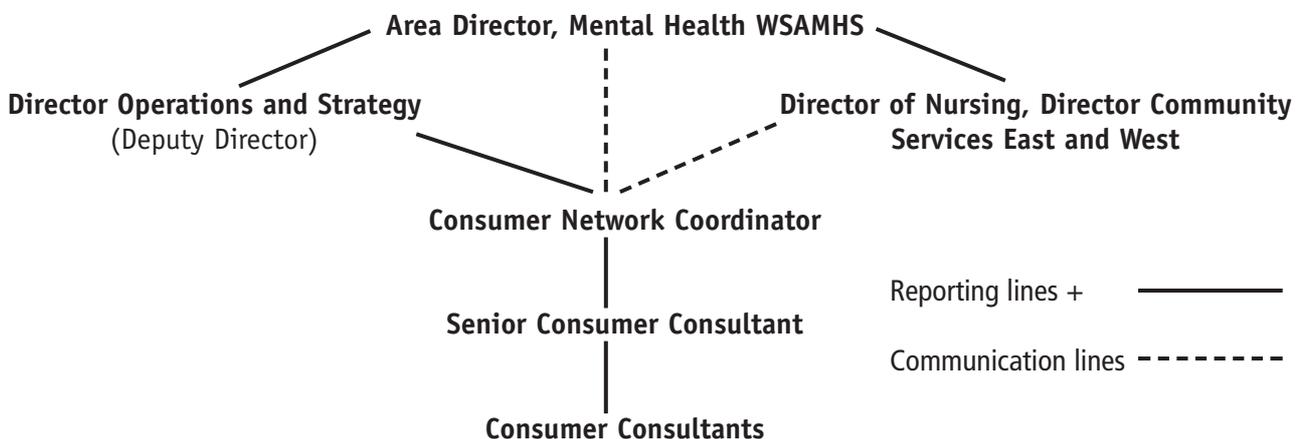
Consumer Consultants

The Role of A Consumer Consultant (CC)

Staff of the Consumer Network participate in the Western Sydney Area Mental Health Services (WSAMHS) with the aim of ensuring the service is responsive to consumer needs, and ensuring the rights of consumers are upheld.

Currently the program has CCs who are interested and/or experienced in the following areas:

- early intervention and young people's programs;
- services for people from non English-speaking background;
- forensic psychiatry;
- aged care psychiatry;
- planning and development ;
- adult mental health (acute and rehabilitation);
- community mental health services;
- gay and lesbian issues.

The program is exploring options to include participation for Aboriginal and Torres Straight Islanders.

Hours

CCs are available between 9am and 5pm Monday to Friday. However, if consumers require individual consumer peer support they contact the CCs office and organise a time that is suitable for all parties involved. The CCs office is usually staffed between 9.30 and 5.00 p.m. Monday to Friday. Outside these hours a message can be left on the answering machine.

CCs can be contacted via telephone or paged.

Roles

Consumer Focus Groups

Consumer Focus Groups utilise a confidential open group approach and are designed to measure:

- participants' satisfaction regarding various aspects of the service (i.e. process, delivery mode, recovery/support, staff approaches, satisfaction with illness and treatment, involvement in care planning, information about rights) or;
- in consultation with the individual teams, the desired outcomes of the program overall.

Model

All consumers who are present at the time of survey are encouraged to attend and participate. CCs utilise an open questioning approach that encourages participation from all members of the focus groups. Additional information can be gathered after negotiation with individual teams/units. If this process is not appropriate for some participants, they may approach consumer consultants through the Consumer Peer Support Program.
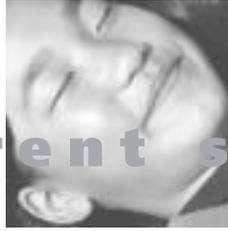
Confidentiality

Confidentiality is ensured for all participants within this process. No participant or staff members' names are recorded in the reports that are sent to the Nursing Unit Manager/Coordinator/Team Leader, after each survey. If CCs are concerned that a consumer is at risk themselves, or a risk to others, they are required to inform a senior staff member on duty.

Reporting

Reports are completed by consumer consultants and returned to the team on completion via the NUM/Team Leader/Coordinator. These reports should be discussed with the team, and comments forwarded to the Consumer Participation Coordinator via the NUM/Team Leader/Coordinator. Any action recommended by the CCs is documented in these reports, and may also be discussed through individual contact with the team or the NUM/Team Leader/Coordinator. Summary of reports, survey recommendations and follow up action are prepared by the Consumer Network Coordinator and presented to relevant committees. Serious concerns and issues that appear repeatedly will be highlighted at these committees.

Consumer Peer Support

The Consumer Peer Support Program (CPS) is designed to provide a more individualised approach to support for consumers accessing WSAMHS. In this way CCs provide support and assistance to those individuals who

- do not feel comfortable interacting in group settings;
- are socially isolated or disadvantaged;
- require support independent of existing MHS or staff.

Individual CPS

Consumers can self refer through the CCs office, or in turn be referred by staff or other interested parties external to the WSAMHS. A CC will visit the consumer and discuss the role of the CCs and assess as to the appropriateness of their involvement. Consumers may receive support from the CCs in an entirely confidential manner, and may be required to assist the consumer by attending Tribunal hearings, encouraging the consumer to advocate on their own behalf or support as necessary.

Group Peer Support

CCs are available on a limited basis to attend units/ programs in a more informal manner to speak and support consumers. Depending on staff levels within the Consumer Network, up to 2 CCs can attend the unit/ program and speak to individuals or small groups (2–3 people regarding issues across the entire Consumer Network. No formal reports are usually presented (although this can be negotiated). Often this is a less formal way for consumers to self refer to the Individual consumer support program.

Attending Magistrate/Tribunal Hearings

CCs will attend magistrate/ Tribunal Hearings when requested to by individual consumer. In this role they may

- support the consumer, and/or
- advocate on the consumers behalf if requested to do so by the individual consumer.

Supply Information to Consumers Regarding their Rights

Information supplied by CCs regarding consumer rights is drawn from the following documents:

- Charter for Mental Health Care in NSW;
- National Standards for Mental health Services (1996);
- Mental Health Act (1990);
- WSAMHS: Your rights and Responsibilities (January 1999).

Other information required by consumers on an individual basis is gathered from resources within the WSAMHS.

Independent Person/Advocate: Empowering Consumers to Advocate

CCs endeavour to assist consumers to advocate on their own behalf. The CC ensures that the consumer has access to all relevant information and processes. The CC will only advocate on behalf on a consumer if it is not possible for the consumer to do so themselves. This may include advocacy to services within or outside the WSAMHS. CCs will only advocate on behalf of an individual consumer when the individual consumer requests that they do so. CCs also advocate for consumers through meetings, committees and reports.

Facilitating Complaints from Consumers

CCs can assist consumers to understand and follow through with complaints. CCs follow the polices outlined within the relevant service.

Attend and Contribute to Management, Evaluation, Development and Other Meetings and Working Parties

CCs attend and contribute to management, evaluation, development and other meetings and working parties as required. Some of these meetings include:

- Western Sydney Area Mental Health advisory meeting;
- food services groups;
- refurbishment committees;
- service evaluation and improvement committee;
- community consultative committee;
- sexual safety committee and;
- individual unit/program meetings as required.

Developing and maintaining consumer and external agency networks.

As part of the Consumer Network CCs are responsible for developing and maintaining consumer and external agency networks. CCs can educate and facilitate the setting up of networks at an individual unit/ program level or at an area level. These networks include consumers, carers, non government organisations, and other agencies/ representatives relevant to the consumers of WSAMHS.

The Consumer Network maintains close linkages with a number of consumer groups including the NSW Consumer Advisory Group, The Mental Health Council of Australia, the National Organisation of Australian CAGs, Consumers Support Workers Forum and the Australian National Consumer Network.

Provide Education for Consumers and Staff

CCs provide education for consumers and staff on issues such as consumer participation and the role of consumer consultants. This role can be done on an individual basis, but usually takes the form of group sessions. Education for consumers in inpatient units occurs on a regular basis, while these sessions may also be utilised to introduce the concepts of consumer participation or consumer programs. Education sessions address such issues as what is a consumer consultant, consumer participation, setting up consumer networks, and what consumer networks are available within and outside the WSAMHS.

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1.4 CANDO: Developing Consumer Participation in a Rural and Remote Area Health Service

Douglas Holmes, CANDO Coordinator, Greater Murray Area Health Service (GMAHS)

This paper aims to provide some background information about the Community Awareness Network and Dadirri Organisation (CANDO) project which started in December '99. The CANDO project provides a coordinated approach for mental health services to have improved participation of consumers and carers in decision making at an Area level. CANDO works with local Area Mental Health Services to link consumer and carer initiatives throughout the area and generate service planning in partnership with consumers and carers to contribute to evidence-based programs in mental health to ensure that the focus is on consumer and carer needs across the GMAHS.

Background

Consumer and Carer Participation (CCP) is not an optional extra in today's mental health services, it is an integral part of service reform and development. It is not something that should be grafted onto service systems, CCP is built into each step and each decision of the management of services. CCP is not a parallel system to management, it is integrated into management systems.

> *Across NSW health system, there are many examples of individual clinicians and health services that do recognise the value of actively seeking feedback from consumers and carers. Some even provide training, information and support to consumers and carers on an ongoing basis so they can work in partnership with health teams to achieve continuous service improvement.* **(NSW Government Action Plan Implementation Group, Consumer and Community Participation 2001).**

In 1992 the National Mental Health Policy was developed to set the direction for reforming mental health care. The goal of the reform was to significantly improve the treatment, care and quality of life for people who suffer from mental health problems and mental disorders.

This project is an example of how we have woven this into the fabric of the Greater Murray AHS.
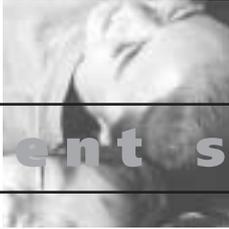
Introducing an Innovation (CANDO QI CYCLE) into a Rural and Remote Area Health Service

When I first joined GMAHS as the Consumer Advocacy Coordinator (CAC) everyone wished me well in trying to introduce CCP across the Greater Murray. On reviewing the literature the '97 Laidley Report, commissioned by Greater Murray made several recommendation including:

> The GMAHS should immediately fund and establish a Regional Consumer Advisory Group to work with the Director of MHS in the future development of the service according to the standards outlined in Section 3 of the National Standards for Mental Health Services **(NSMHS)**.

Greater Murray applied to the NSW Centre for Mental Health (CMH) for some enhancement funding in 1999. The Centre included a number of conditions for the project. The conditions fondly known as "Attachment A3" have been adopted as the objectives of the project.

- a plan for prevention, promotion and early intervention developed in partnership with consumers and carers;
- increase consumers' and carers' contribution to evidence-based programs in Mental Health
- a whole of life approach which addresses the needs of specific consumer groups, especially young consumers;
- a focus on outcomes and recovery;
- broadening the base of participants in Consumer and Carer programs (including volunteers as well as involving members of the broader community outside the mental health field);
- the need for group empowerment and other initiatives.

The Greater Murray is a very large land mass, larger than Tasmania 113,654 kms, population of 252,000, 9 Health Networks, 29 LGAs, 43 Community Health Centres and 2 Acute units with 34 beds.

My first public foray in the area was a morning tea and talk in Albury. I talked about my own experiences and with some enthusiasm about what I hoped to achieved in the 3 years that the project was funded for.

Trust

I continued this process at each of the many facilities across the GMAHS. It was important to gain the trust of staff and reduce their suspicion of and resistance to CCP. This was usually an informal talk and involved the first of many field trips to some of the outlying areas. The informality was particularly important for the mental health staff who were not used to attending formal talks, seminars or education sessions from either consumers or carers.

Model

The model I had decided I would base my work on was "Mental Health Consumer Participation Project– A toolkit for Mental Health Consumer Participation" by Patricia Nolan Ph.D.

The Toolkit for Mental Health Consumer Participation was written up in 1996 and is about the development of consumer participation for Mental Health Consumer Advisory Groups across Queensland from 1994 to 1996.

Name and Logo

During this time the name for the project and logo started to emerge. The CAN stands for Community Awareness Network, which covers the stigma still associated with mental illness. The D is an aboriginal word that means to "to listen to each other" and the O stands for the organisation or structure that is necessary to keep the project moving forward.

The logo came about because of the need to have a symbol that people could identify with. The Area-wide CAG working group was involved in developing the colour scheme. The blue roof represents that the sky is the limit with what we are trying to achieve and in the many meetings is the only decision that has needed to be voted on.

Formation of the Area-Wide CAG Working Group

There was no point in talking about CCP as an abstract concept. Staff wanted to known what the new CAG was expecting of them. Very soon I published an area-wide new sheet, information sheet and consumer and carer survey which I distributed very widely for comment. It was important to be seen to be inviting comment and to set the precedent of expecting that staff, consumers and carers would have input into CCP.

This process allowed me to identify where the resources were (staff, consumer, carers, other interested people and equipment) to build the network. It also identified where gaps were and where linkages needed to be built.

Many more kms and lots of meetings and cups of teas have helped establish a viable network across GMAHS. Where consumers and carers were available we made a time to meet and find out what they wanted to achieve. Several local groups have been established from these initial contacts.

Representatives from these local groups were invited to participate in an area-wide meeting in Wagga Wagga on November 24, 2000. This core group has continued to meet every couple of months in Lockhart. The main task of the working group was to agree on some key principles contained in "The Toolkit":

1. Empowerment
2. Support
3. Formal Mechanisms
4. Formation
5. Process
6. Functions
7. Structure
8. Strategies
9. Resourcing
10. Exchange of Information
11. Outcomes

More information about this process is contained in the report "Formation of GMAHS Area-Wide CAG 2001".

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What future for the CANDO Project?

The future for CANDO looks bright:

- a large group of consumers, carers and staff is participating in this conference;
- a position paper has been sent up to GMAHS Board of Directors (BOD);
- an Expression of Interest form has been developed in anticipation of the
  BOD supporting the groups preferred option;
- several local group's have been started;
- CANDO checklist is being discussed at the area and local management advisory committees.

Has there been real improvement in service?

The process has made changes to the way services are doing business. For example, at the GMAHS Mental Health Area planning forum 5 members from different local CAGs were invited to participate in the two-day event.

The experience and knowledge people have gained from CCP will continue to grow in Greater Murray.

This highlights the fact that the process of undertaking CCP can be as important as the final outcome.

What does CANDO do?

The role of the CANDO project is to support the development of Consumer Advisory Groups (CAGs) in the Greater Murray to:

- provide networking support, advocacy and information to mental health consumers
  and carers who live in the Greater Murray Area;
- ensure the sustainable development of a network of CAGs across the Greater Murray,
  including one area-wide CAG;
- achieve long term, promotion and coordination of mental health consumer
  participation and consumer and carer initiatives within the Greater Murray Area.

What does CANDO offer?

CANDO offers a range of services for Mental Health Consumers and Carers, including:

- a regular newsletter;
- area-wide consumer and carer meetings;
- phone contact and support.

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1.5 Ryde Mental Health Consumer Network: A Partnership in Caring

Paula Hanlon

Background

The Ryde Consumer Network was established in November 1993 by Michael Appleton in an office within the Mental Health Services building. Michael had been participating on a committee to oversee the closure of Gladesville Hospital and pre-empted the support of Northern Sydney Mental Health to the support of a Consumer Network. Ryde is a sub-area of the Northern Sydney Health Service Mental Health Consumer Network formally established in February 1994. Michael Appleton was one of the founding members of this Area network.

Early Days

The early days of the consumer network were a struggle. The office was very small and there was no meeting space for consumers on the premises. The mental health workers did not fully understand or accept our role. In the first two years the role of the Ryde consumer group was to run consumer meetings. In 1995 a consumer representative began attending a fortnightly staff meeting with the Acute team informing them of the activities of the Network, promoting membership for consumers. Gradually an attitude change to consumer participation occurred, with some mental health workers referring people to the consumer network. The Management of Ryde Mental Health Service was very supportive and the team leader became an accepted part of the management committee.

Consumer Network Guidelines

In 1996 the Ryde Consumer Network Mission Statement/ Aims and Objectives and Guidelines were written and endorsed by the Consumer Network and the Ryde Mental Health Management Committee. In 1997, the Area Consumer Network developed Guidelines and Code of Conduct, which have been reviewed twice since then. An Area policy titled "Consumer Participation and Partnership" was established in 2000 that covered participation at the individual treatment level and partnership at the systemic advocacy level.

Membership

The membership of the network fluctuates. People join the Network, recommended by case managers, psychiatrists and other consumer representatives. People develop skills, improve self esteem and confidence, then move on to employment or tertiary studies. The membership averages around 16–17.

Consumer Employment

In January 1998, Ryde Mental Health Service employed the Team Leader position initially for 8 hours per week. In August 1998 it increased to 20 hours and since January 2000 the position has remained at 24 hours per week. A Consumer Facilitator position was created in October 1999 at the Hut, the recreation and leisure centre for the people from the Ryde area.

An Integral Part of the Mental Health Service

In September 1999, Ryde Community Mental Health Service moved to new premises in Fourth Ave Eastwood on Ryde Hospital site. A consumer representative was active on the committee planning and designing the purpose built building. Consumers were provided with a large room for the Consumer Representatives office, meeting space and a place where consumers can relax, have a cuppa and a chat while waiting for appointments. The Consumers' room includes a resource library for people to access information on the various mental health problems, rights and responsibilities, policies and services available within the mental health service and broader community.

Roles of the Consumer Network

Consumer Representatives attend a variety of meetings where they participate with a broad outlook. These meetings include the Management Meeting, Mental Health Partnership and Promotion, Department of Housing/Mental Health Liaison, Ryde Hunters Hill Interagency. The consumer representatives meet monthly to discuss local and broader issues, training, conferences, forums, and selection for meetings. The consumer network has a weekly advocacy program at the local inpatient facility at Macquarie Hospital, which consists of 1.5hours in the unit and a half hour debriefing. Advocacy support is available for people in the community who are experiencing difficulties with accessing the mental health services or concerns with the service(s) they are receiving.

Consumer Representatives and advocates attend training and are provided with ongoing support and professional development.

The consumer network has developed information and rights packages which includes all the service brochures, rights and responsibilities information, the complaints process, information on the National Standards for Mental Health Services and NSW Charter for Mental Health. A consumer forum is held bimonthly with guest speakers and/or topical discussions where the consumers' feedback is reported to a service committee (such as the management committee, rehabilitation service) as input into planning and review processes.

Social Club

In February of 1996 the Consumer Network Social Club was created to organise social activities. The first dance was held in February 1996. For the first three years (1996–1998) there were 3 dances a year, February, June and October. Since 1997 the October dance has had a Halloween theme, where costumes are optional. From 1999 only two dances a year have been organised. The dances are attended by people from all over Sydney, including Liverpool, Bankstown, Emu Plains, Penrith, Cronulla, Glebe, Marrickville, Leichhardt, Croydon, Hurstville, Parramatta and as far away as Gosford and Katoomba. The Consumer Network guidelines prevent the use of funds for social activities, therefore dances are self supporting through ticket sales and fundraising. The numbers attending the dances have ranged from 60 to 120.

The Hut

The Hut opened in 1999 with the Consumer Network Social Club amalgamating to form the recreation and leisure club. The Hut daily decisions are made at a Coordinating Committee consisting of 10 consumers (5males, 5 females and the consumer coordinator) and a staff representative from the CREATE team. The Hut Steering Committee (Deputy Director and Team Leader of Rehabilitation, Team Leaders of Create team and Consumer Network and the Hut Consumer Coordinator) meet bimonthly to oversee any policy or service development issues.

The Hut is an affordable place where people can socialise, free of stigma. It has a very different atmosphere to the old "living skills centres", as consumers are more than just participants of activities they are active partners in the running of the service—a place where they can have a real say—there is a real sense of ownership and belonging. The Hut organises a range of optional activities including; holidays (e.g. Blackheath), Royal Easter Show, the Olympics, Theatre, sporting competitions (e.g. NSW Soccer and ten pin bowling), Mental Health Week Cricket:Consumers 11 vs Minister's 11, and day trips. There is a womens and a mens group. The program also includes "Healthy Lifestyle" activities such as yoga and aqua aerobics.

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2.1 Children Living with Parents who have a Mental Illness

Margaret Cook

I will present how persistence has paid off after many years of raising awareness about this issue. I have taken many risks and been vulnerable not only to staff but to consumers also. Due to the sensitive nature of this issue and the intensity of the parent bond relationship, I have been vigilant to not diminish either the parent or child while negotiating with all levels of professionals. I have become aware during this time how little the provider knows to which service these children belong and who should provide the service and how. Whose responsibility is it to do this? I have been working together with the Interagency Collaboration for Children of Parents with a Mental Illness (ICCOPMI). We have won a 2000 Community Services Industry award that acknowledged the collaborative nature of the network's successes. *Abstract*

2.2 More Than a Handshake

Maggie Lawson

Suicidal ideation and attempted suicide by survivors of child sexual assault can be met by contempt, dismissal and blame. Often the persons and institutions the person turns to help recreate the previous abuse. We believe real prevention requires a space for the adult survivors to speak freely and comfortably, participate in the development of effective responses and treatment models and ensure these initiatives are adopted by local health services.

The presentation suggests a need to act collectively to bring changes to support adult survivors and explore the dynamics of the relationship between workers, survivors and women in the community. *Abstract*

2.3 Grief and Loss: an Aboriginal Perspective

Ngiroo Health (good mind but tired): Cynthia Schuhmacher

I am a Wradjuri woman. I will speak about positive ways forward after a grief, as an Aboriginal woman survivor/consumer. It is time to explore ways in which our spirit can be healed in a holistic way. I will speak about gambling and alcohol and how these two addictions can be used to block the grieving process. I will share my past eleven years as a consumer advocate and touch on my trip to New Zealand. I will also explore how some of the mainstream and conservative churches need to be educated and more aware of the human emotion and spirit. *Abstract*

3.1 Why *Mind Matters* Magazine?

Nicky Cheshire

I have been a physiotherapist for twenty-two years and for the past eleven years I have been blessed with the most important job on the planet, that of being a mother. I have two lovely girls aged eight and eleven. My other qualification is MD, which I obtained at the age of thirty-one. Although I did want to be a doctor when I was young, I was not very happy with my MD initials, because they stood for Manic Depression.

I have actually had difficulties with my Bipolar Disorder from the age of sixteen, and have experienced both poles many times. I have been scheduled ten times. I have seen the inside of many different psychiatric hospitals and varying degrees of comfort, from the five-star clinic in Chelsea in London (where the food and facilities were excellent and I booked in for regular saunas and facials) to an institution in the West Country of England which had cages on the lawns only twenty years earlier. Even worse, from my perspective were the wire mesh walls in Kathmandu's hospital. Although they may have been practical for the heat, or was all they could afford, I really felt I was in a cage there.

I came to Australia in 1987 on a six month working holiday visa, fell in love with the bush, the weather, the people and a man. Although I thought I would never be ill again (has anyone else had that experience?) I continued on the Bipolar roller-coaster when my first child was two weeks old. Then I discovered that although the treatment for psychotic episodes here is horrendous and humiliating, the end result of needles and the solitary confinement room in the acute ward was, for me, quicker and eventually less painful than the prolonged, heavily drugged experiences I had in England. I went through hell again during a depression when I was six months pregnant with my second child. I was informed I had to have an ECT as the anti-depressants would be harmful to the foetus. To be honest, at the time I just wanted to die with the child. However the treatment worked and my baby still had two arms, two legs, two eyes, two ears etc.

After these and many other experiences, plus my MD qualification I decided I wanted to do something to help others with a psychiatric disability here in Sydney. [The diagnosis of MD was never given in the UK. My experiences were just described as endless nervous breakdowns.] I had a variety of ideas but I did nothing for anyone else for a long time. I was busy surviving, living with my separation, learning about myself and working on a constant battle with my self-esteem.

In July 1998, while I was in a newsagency looking for pictures of boats for my dream book, I was suddenly inspired to do something about the disgraceful gap - there were endless magazines on every subject except mental health issues. It was a very overwhelming moment and I remember crying for most of that afternoon. I was excited but scared at the thought of a magazine - but I knew it had to happen. I did some brainstorming among friends and colleagues and I was able to register **Mind Matters Magazine** (my preferred name) on 29 July 1998.

Unfortunately I became psychotic a few days later. However with a fraction of insight and an excellent psychiatrist I stayed out of hospital and self medicated. That episode was enough to bring my fears to the fore

and I did nothing with Mind Matters Magazine for many months. I was scared for myself because my personal journey had been so horrific at times. I knew that working with the magazine would bring up a lot of my past which I felt may make me vulnerable to further episodes. I was also scared because I knew nothing about magazines. And how could a physiotherapist start a magazine?

These problems seemed insurmountable. However in December 1998, a mother from our local school committed suicide, leaving three children aged five and under. The five year old was a friend of my younger daughter. The next month (January 1999) a friend's son committed suicide, leaving his three year old daughter, who was in his custody, to be brought up by her grandmother. These suicides shook me out of my fear stupor because I know what it is to be left behind after a suicide. My mother committed suicide when I was seventeen and my younger brother was five. I also have an older brother who was away at sea at the time. He too suffered the dreadful long term grief that the unexpected loss of someone you love causes.

So early in 2000 I began networking and talking about the magazine to as many people as possible. The first health professional I spoke to was my psychiatrist. I know that if he had been negative or worried about my health I would probably abandoned the idea. However he was very encouraging, as he was aware that I had been keen to do something for a long while. Shortly after that my "crank handle" at church, our pastoral care coordinator, suggested I contact Meg Smith at the University of Western Sydney. Meg was very helpful and started me on the round of professors and various organisations.

Along the way I have had help from so many people at the most opportune moments and so many remarkable experiences that I knew Mind Matters Magazine would happen. I realised at the beginning that I would need maximum help because of my lack of knowledge of magazines. One of the many people to help me was David, the father of three motherless children. After several months of talking about the magazine, David suggested I needed a method of collecting names for a database. He produced a very simple piece of paper, with a space for a name and address, which I distributed while standing next to a whiteboard and poster at church for a few Sundays. Later, when the committee was more formalised, he helped design the Does Your Mind Matter brochure.

Now, nearly three years from those first single-handed beginnings, we have a small but committed team who are determined to make Mind Matter Magazine happen and a database of nearly five hundred supporters that is increasing daily. Just this week we have had responses from Cairns, Tasmania, South Australia, Victoria and plenty from New South Wales. The Wesley Mission are now assisting by sponsoring these brochures and we have formed an association with their Depression Foundation. Rotary is also including brochures in the participants' packs for their Nationwide Forums on Mental Health.

So why Mind Matters Magazine?

We believe it is time for one magazine to bring together all the different areas of mental health and to advertise at conferences such as this, work opportunities, TAFE courses, rehabilitation programmes etc. Many of you, I expect, are already on our database, but for those who are not, the aims of the magazine are to:

- broaden public discussion of mental health issues;
- provide education on mental illness and encourage early diagnosis;
- breakdown barriers and reduce the stigma attached to mental health;
- give hope and empowerment to people with a mental illness, and to their carers;
- promote awareness of the significance of stress in the workplace and society;
- help reduce the occurrence of suicide.

There are many people who needed this magazine yesterday; to give them hope, ideas or knowledge of mental illness and the myriad issues surrounding it. There will be even more people who will need it tomorrow. Most of us are aware that on average seven people a day commit suicide in Australia. That is horrendous. How would that affect you if it was your mother, or father, or brother, or sister, or son, or daughter, or best friend?

I believe the only way to improve the situation is to encourage people to be open and talk. I agree with Jeff Kennett's goal (former Premier of Victoria) to make the discussion of depression as easy as talking about the common cold. I wonder how Beyond Blue intends to achieve that goal as they have refused sponsorship for this magazine. So far we have not found the funding for a good quality, credible, sustainable magazine; but we will not give up.

Stigma is ever present. At one of the recent Rotary forums during Mental Health Awareness Week, a doctor was speaking about the death of his son who had schizophrenia. Afterwards he said to me "I would never have picked you for bipolar." Even in the medical fraternity there is still that gap between them and us.

During some of my manias in London I wanted to utilise all the intelligence of those people stuck in hospitals and institutions. From my experience most of us with a mental illness have reasonably high IQs, but the wiring or the chemicals in the brain are not functioning correctly, and sadly much of that intelligence is wasted. Perhaps the magazine will also encourage people to realise their full potential.

I remind you that Mind Matters Magazine is coordinated by volunteers. If you feel this is a worthwhile project and would like to assist with anything from data entry, editorial work, networking, sponsorship, media relations or computer work, please contact me.

I would like to see my children, grandchildren and their children face less stigma, isolation and humiliation if they have any mental illness. I would also like to see greater community knowledge and acceptance of mental health issues. I believe Mind Matters Magazine has a significant role to play in this process.

Nicky Cheshire
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3.2 A Celebration of Recovery and Community Participation

Leanne Nicholas

Recovery is a journey to wellness and developing strategies to aid a sense of belonging and giving back to the community. Sometimes it involves reassessing previous goals. In 1993 I was a twenty-one year old student attending university in Canberra, living away from home, when my Grandmother, with whom I was close, passed away. I began to experience paranoia, auditory hallucinations, negative mental images, mood swings and depression to the extent where I lost the concentration needed to study. I returned to Sydney, and to my family, and so began the long journey for me to accept my illness and also for my family to accept it.

My mother spent a lot of time just being with me, and we went on lengthy daily walks together, where no dialogue took place as I was so caught up with dealing with the voices in my head. Exercise has helped me have a positive attitude and without the support of my mother and other family members I would not be here talking to you, instead, I would be watching Oprah, and unable to carry out basic household chores. I made four attempts at studying again at Macquarie University, with only partial success as the voices would distract me from reading. I also had trouble motivating myself.

The turning point for me in the acceptance of my illness came when I began to realise that this path of University was not bearing fruit for me at that time. It was then that Paula Hanlon from the Ryde Consumer network suggested I become a representative of consumers for the area, which involves working in partnership with other people with a mental condition. After being a consumer representative for a number of months, Paula invited me to undertake consumer advocacy training, which involves peer support for mentally ill patients in hospital. It was an exciting challenge to learn about mental health standards and I felt stimulated knowing I could potentially use this knowledge to support people through their hospitalisation and really make a difference. Soon after I gained my first paid position as a part-time consumer advocate at Macquarie Hospital. This gave me more confidence, and I felt that I was able to develop skills that I could use to benefit others.

I have also been involved with other organisations that focus on health promotion. One is the establishment of Mind Matters Magazine, a Magazine about mental health that aims to inform the general public, health professionals, carers and consumers of mental health services, about mental health issues. This idea was conceived by Nicky Cheshire, a physiotherapist and mother who has bipolar disorder.

I am involved in Mental Illness Education Australia, or MIEA, which trains consumers and carers to visit high schools and community groups to raise awareness of mental health, educate people, break down stigma, and provide help-seeking avenues. I find presenting to schools and communities extremely rewarding, reaching out to groups in society that are touched by mental illness even though they may not know it. One student said of the Programme, "They helped me understand because they weren't facts read; they were real stories influencing me with HUGE IMPACT. Thanks!"

Another aspect that has helped me in recovery is a support Group called Australian Society for Students with a Mental Illness. By joining this group, facilitated by Yvette Cotton, I was able to meet people with a mental

illness who also had a common interest in study. It has monthly meetings at Friendship House, Gladesville, and social outings.

I recently did some interviewing and acting in an educational video, which was fun and another way of developing friendships. The video is is a project of the Mental Health Association of NSW, aimed at advising people how to run mental health support groups. Other speakers will talk about this later in the conference.

Another contribution to my recovery is my spiritual practice as a member of Sukyo Mahikari Australia. It has helped me accept my illness and see the blessings that I receive in my daily life. Today I can celebrate my recovery and help and inspire others on their road to recovery to participate in the community in this year, the international year of the volunteer, and in the future.
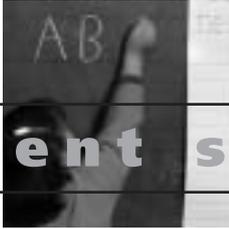
3.3 Personal Stories: How to use them as an effective training tool

Gary Platz

I have used my personal story of my experience of mental illness many times over the last few years, either at public speaking engagements or workshop training. I have also told my story on national radio (NZ), national television (NZ) and in Daily Newspapers. The response to those public self-disclosures is overwhelming. Months later complete strangers make comment on how on the powerful insight they gained. The question that always comes to my mind is why does disclosure about the mental illness experience create such a reaction?

In fact there are several reasons which, when combined, answer that question for me.

- **Storytelling** is a powerful teaching and communicating medium. *Storytelling evolved from the human need to communicate experience to other humans* ***(Anne Pellowski, The World of Storytelling from R.R.Bowke, 1977)***

- **Storytelling** contributes to development of social and cognitive development through shared experiences ***(Baker, p.18)***

- **Self-disclosure** (Self-disclosure is defined as sharing information that they would not normally know or be able to discover.) Appropriate self-disclosure is a powerful tool for enhancing the learning process because it can foster a strong relationship between the speaker and the participants. It also creates an implication that the participants will respond in a self-disclosing way. This is known as the "norm of reciprocity". Mutual disclosure deepens the trust in the relationship between the speakers and the participants and helps both with a better understanding of each other. ***(Guidelines for Personal Disclosure for Teachers: Rachael Kessler)***

- **The experience of mental illness is very powerful**. Mental illness is extremely powerful. It causes one to act, feel, think, etc. in ways that one would never imaged possible for them. It is an experience that reaches right to the core of our very being. It challenges our very existence. In surviving these experiences then integrating the experiences to the extent we can appropriately self disclose means we to have gained personal power. Our audience responds to this.

When we have a combination of those factors the historical strength of storytelling, the connecting power of appropriate self-disclosure and the person power of surviving mental illness experiences to the extent we can publicly talk about those experiences it becomes clear why people respond the way they do.

How do we Disclose Appropriately?

1. Teach not shock

This is something we really need to be careful about. Our experiences are big and for most of us they have been kept in secret. So when we do disclose publicly there may be a strong desire to let it all out so to speak. Remember the purpose of your disclosure. Is it to shock people or is to help with their understanding. It is impossible to learn when traumatised.

2. Only disclose things that you have integrated

If you share some thing that you have not integrated, something that is raw, unresolved or too shameful this will have a detrimental effect on you. It will also damage the connection you have with audience or participants and harm their learning process. Also anger is always close by unresolved issues.

3. Stick to the purpose of the discourse or lesson

Always share what is of value to the audience or students experiences that are in line with the purpose of lesson or discourse. The process of self-disclosure can almost therapeutic but that is not the purpose. It is to teach and enlighten. The audience or is not there as a support group. Never use an audience as such.

4. Keep to the point

Do not ramble. Know what it is you want to say. Know why you want to say it. That does not mean you need to be word perfect but have main points and keep to them.

Risks

• Participants or a participant may not respond favourably

Self disclosure does not automatically mean a favourable response.

Ways to minimise the chances of this:

- establish an identity with the audience (who you are, your credentials for doing the discourse);
- create a safe environment through good ground rules and a welcoming feeling;
- disclose in line with purpose;
- do not become too personal too soon.

• Speaker does not trust the audience or the process of self-disclosure as a safe teaching tool

If you do not trust the participants you cannot disclose safely. If you do not trust group process you cannot safely disclose. It would be emotionally dangerous to self-disclose in those circumstances.

If you feel this happening have other people's stories to fall back on but first check if you have created a safe atmosphere for audience with ground rules etc.

• You cannot completely predict the response of participants

Disclosure will always be a risk. You cannot control how people respond but if you take into account the things outlined above you can be confident of good outcomes.

• Need for debriefing

We need to be aware that self disclosure does have an emotional effect on us .It brings things to our attention that we may not normally think about or even have been aware of before. So we do need debriefing and some self-nurturing after a speaking or educational session.

In conclusion I would just like to leave you with this thought. Everyone who has survived mental illness has a powerful story to tell. Can you imagine a difference it would make to how people who have had the experience of mental illness would be view by the general public and authorities if every on in Australia heard those from each and every one of us? Literally hundreds of thousands of experiences all heard by everybody.

We all have some think valuable to offer and I hope what I have presented will be of value to you.

3.4 Mental Illness Need Not be a Barrier in Reaching Meaningful Employment
Rick Austin

This paper outlines possible disadvantages in the labour market for some people suffering from mental illness and discusses a number of possible barriers that may hinder employment for this group of people. The paper is interactive, fun and entertaining and uses a number of different mediums to illustrate points including overhead transparencies, whiteboards and magic. *Abstract*

4.1 CEO-MHS: Forging our future through evaluation

Gillian Malins, Jon Strang, Gordon Lambert, Yvonne Eman, Lindsay Oades, Linda Viney, and Kate McKeehan

The aim of Consumer Evaluation of Mental Health Services (CEO-MHS) is a research partnership to be forged between university researchers and consumers to develop a method for evaluating mental health services from a consumer perspective.

This presentation will outline the aims and design of the three-year project, and discuss our experiences of collaboration in the first stages of the project. The implications this research has for partnership at various levels within mental health services will also be discussed.

The project consists of two stages, which will be outlined in this presentation. The first stage will consist of development of a model and evaluation instruments. The second stage will involve trailing these instruments in an Illawarra Area Health Service site. The nature of the partnership between consumers and university researchers during these two stages will be discussed.

What we hope to do today is provide you with an overview of the CEO-MHS project and to discuss the partnership between mental health consumers and academic researchers that is the core of the project. CEO-MHS is a three year project funded by the Australian Research Council, the Illawarra Area Health Service, and the University of Wollongong.

Aims and Design of CEO-MHS

The overall aim of CEO-MHS is to develop a set of tools or questionnaires from a consumer perspective that can be used to evaluate mental health services. These will be i) a consumer survey evaluating mental health services; ii) a staff survey evaluating mental health services; and iii) a mental health services organisation self-assessment protocol.

A major limitation of the surveys currently used to measure consumer satisfaction with services is that most are based on satisfaction defined by providers, rather than consumers (Campbell, 1997; Perkins, 2001; Hansburg et al, 1996). CEO-MHS aims to develop methods of evaluating mental health services based on consumers' views.

A further aim of the project is to document the research process, so that other area health services, or researchers, can perform a similar type of research, learning from our experience. Once the instruments have been developed, they will be trialed within IAHS sites, as a demonstration.

The research will be conducted in two stages, which reflect the aims above. Each stage involves collaboration between university-based researchers and consumers.

The first stage will involve achieving the aim of developing the set of questionnaires. Focus groups will be run by Consumer Researchers to find out from consumers what questions we need to ask about evaluating mental health services. Analysis of the focus group discussions will result in an interview guide, which means that the questions guiding the interviews will reflect issues that are relevant and important to consumers.

The major source of information from which the questionnaires will be developed is consumers' experiences. Interviews will be conducted with over 100 mental health consumers in the Illawarra and Shoalhaven regions. The purpose of the interviews is to find out from consumers what they view as important in mental health services, and what 'evaluation' means to consumers.

The interview responses will be analysed for themes. Two Consumer Researchers and Gillian Malins will do this work. These themes will then form the basis of the questionnaires. Gillian and a larger group including Consumer Researchers will develop the themes into questions.

The second stage of the project involves trialing the questionnaires that we develop within the Illawarra Area Health Service.

At its most fundamental level, CEO-MHS aims to empower consumers' through "credible" research. There seems often to be a divide between consumer research and academic research: this project is an attempt at merging the two. Consumer input brings the expertise of 'living' to the research - as well as the many other skills individuals have. This will (it's hoped) make the research relevant and useful to consumers, as research performed solely by 'non' consumers cannot. The KIT (1999), a product of the Community Development Project highlights that mental health consumers' still lack credibility in the eyes of some service providers and others. By creating a partnership between academic and consumer research, it is anticipated that CEO-MHS will challenge views that consumers' lack credibility.

For this research project to be empowering in any way for the consumers involved, it is important that a genuine partnership is worked at and that the academics involved do not take over the process. Likewise, neither should the consumers within the team take over the process. What we hope to achieve in contrast to either of these scenarios is a balance of input where each of us acknowledges what each other team member brings to the research in terms of knowledge, experience and expertise. Some of us know more about what consumers want, need, experience and fight. Others of us know more about how research might be run to achieve our aims.

It is this partnership that we would like to discuss further today.

Experiences of collaboration in the first stages of the project

Collaboration at various levels has been built into this project. The project aims to forge an effective collaborative relationship between university researchers, and mental health consumers, as well as Mental Health Services. Each of these groups has expertise to offer research such as this.

The project management committee consists of academic and consumer representatives:

> Associate Professor Linda Viney
> Dr Lindsay Oades
> Mr Gordon Lambert
> Mr Jon Strang
> Ms Yvonne Eman

Other additional researchers form the core project team include:

> 14 Consumer Researchers, a Project Officer, Kate McKeehan, and two students,
> Rebecca McLeod a Clinical Masters Student, and Gillian Malins, a PhD student.

The team also collaborates with 2 external consultants, Dr Barbara Tooth and Mr Simon Champ.

I want to briefly touch on my perspective of the collaboration process, discussing some specific experiences.

In June we held a workshop, which was designed to both let the community know about the research project, and gain some feedback from consumers about the project.

The workshop was an experience in collaboration for the project team at several levels. Not only did we have a series of comments raised by consumers to address and consider, but issues that were raised by consumers at the workshop related specifically to the collaborative nature of the research. Partnership between consumers and researchers was highlighted as both a positive and possibly negative aspect of the project.

Challenges in collaborating were highlighted, for example:

- the need to find a common language and gain an understanding of one another's language;
- the risks of researchers taking over, and "colonising" the consumers involved;
- what is the nature of partnership within the project, and how are the power balances and imbalances negotiated?

Many of the issues raised at the workshop are ongoing challenges for the project team as a whole. Collaboration is occurring in different ways, between different groups. At one level there is the collaboration between researchers and consumers working on the project team. At another level is the collaboration between the project team and the participants in the project: who will be mental health consumers?

We face, and are negotiating, some of the issues around partnership and collaboration within the project team in developing a support and supervision protocol. This begins to make explicit the roles different team members play, and addresses concerns about Consumer Researcher burnout, learning needs etc. raised at the workshop. A fundamental aspect of this is that an ongoing dialogue needs to occur between all team members, with the consumer researchers particularly, in terms of support and supervision needs.

Currently the team is working on developing the format and guide for the focus group discussions. In planning the focus groups, collaboration and the nature of partnership are being explored at both levels: between team members and the team and participants. Within the team, we are facing the challenge of merging the Consumer Researcher's advice and proposals, with the methodological recommendations of the management team and consultants. We are facing some of the dilemmas raised during the workshop relating to the nature of the partnership, and power differentials. The management team is attempting to meet the aim of having a consumer perspective, while honouring the notion of partnership, which calls for use of their expertise in research methodology.

In terms of collaboration with participants in the research, the team is attempting to develop a format that allows consumers to genuinely have their say, not be led by the questions posed.

concurrent sessions

Conclusion

We see this project having implications for partnership within research, and within mental health services. At a local level, the project is forging stronger ties between university-based researchers, consumers and the IAHS. Additionally the project will result in a group of consumers skilled in research, able to take on other projects.

The National Standards for Mental Health Services (Commonwealth of Australia, 1997) includes 'Consumer Participation' which incorporates consumer involvement in planning, implementation and evaluation of services. This project will have obvious impact on involving consumers in evaluation of mental health services, however it is hoped that through the collaborative nature of the research, and by involving consumers in the planning and implementation of the project, it may also impact on these within the context of services.

We hope to have completed the focus groups before Christmas, enabling interviewing to begin early next year.

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4.2 The NISAD Schizophrenia Research Register: Citizen Profiles.

Jim Sheedy
Introduction

NISAD (Neuroscience Institute of Schizophrenia and Allied Disorders) is the first research institute specifically dedicated to the study of schizophrenia and allied disorders in NSW. To enhance and facilitate scientific research into schizophrenia, NISAD has developed and maintains, the Schizophrenia Research Register. The Register is a volunteer database for people with a clinical diagnosis of schizophrenia who are willing to consider participation in research projects concerning schizophrenia. These people are also citizens within our community. The data collected and observations by the researchers can provide an interesting picture of this unique sample of the community.

The Register

The Register currently has over 500 people with schizophrenia, resident in NSW, registered with the database. Recruitment for the Register is undertaken via three sources:

1. Community awareness campaigns involving television, radio and newspaper advertising that specifically target people with schizophrenia, their family and friends;
2. Promotions within the health industry, community support sector and consumer groups;
3. Presentations at research forums and conferences.

At this stage approximately half of the people on the Register have also undergone a clinical assessment to both confirm diagnosis as well as collect important demographic, clinical and neuropsychological information about the illness. The clinical assessment protocol includes:

- confirmation of diagnosis (Diagnostic Interview for Psychosis; DIP), [Jablensky, McGrath & Herman, 1999];
- a measurement of retrospective IQ (National Adult Reading Test - NART), [Nelson, 1982];
- neuropsychological functioning (Repeatable Battery for the Assessment of Neurological Status; RBANS), [Gold, Queen & Buchanan, 1999];
- symptomatology rating (Positive and Negative Syndrome Scale - PANASS), [Kay, Fiszbein & Opler, 1997];
- general functioning (General Assessment of Functioning; GAF) and;
- drug and alcohol history (within the DIP).

The Register and assessment data is accessible to clinicians and researchers interested in investigating schizophrenia and allied disorders. Through the Register NISAD can also assist researchers with subject selection and research participant recruitment. Moreover, the Register provides access to valuable information about schizophrenia, particularly in relation to community (volunteer) based samples that might not be obtained through inpatient samples alone.

Citizen Profiles

Our society seems to have a stereotype of what is thought to be a good citizen. This can include a person who is educated, self reliant, honest, of sober habits, contributes to the community and is a good neighbour. The stereotype of a person with schizophrenia can be somewhat different and influence the stigma associated with this illness [Kommanna, Mansfield & Penn, 1997]. The stereotype of a person with schizophrenia may suggest someone who is dangerous, intellectually disabled, suffering from multiple personalities, unpredictable or unable to make a social readjustment in regard to their illness [Sugiura et al 2000]. The process of engaging with the Register volunteers has raised some contrasts and questions about such stereotypes.

As the following Table of preliminary results shows, Register participants are largely Australian born (84%) and have a mean age of onset of 20.5 years. Most live at home (53%) and are single (65%). The average age of the sample is 39 and 4% are of aboriginal decent. Only 33% have a history of tobacco use while 82% indulged in alcohol. Thirty eight percent are engaged in either full-time or part-time work. Additionally, a number of these citizens are involved in volunteer work in their community or with their fellow consumers.

TABLE 1: Sample demographics of Register volunteers who have been assessed.

Participants born in Australia	84%
Aboriginal decent	4%
Living in family or own home	53%
Currently married	14%
Currently single	65%
Lives alone	33%
Receive Disability Support Pension	65%
In full time or part time employment	38%
Wage earners	21%
Engaged in continuing education	30%
Participants with history of alcohol	82%
Participants with history of drugs	50%
Participants with history of tobacco	33%

Source: Loughland, Carr & Lewin, 2001.

Contrasts to the Stereotype

The Register volunteers are reasonably well educated, only 5% left school with no qualifications. Many are self-reliant; they work, study or seem to cope reasonably well in their community. Very few have interactions with the police or the legal system; therefore they may be considered fairly honest and safe citizens. Their sobriety is perhaps not too dissimilar to the average Australian's. They contribute to their community as volunteers by being involved in activities like Meals-On-Wheels, playing music to aged people, assisting with council run community transport and emergency services. All of them volunteered to help other people with schizophrenia by joining the Register. Most can be thought of as good neighbours as they can participate in their household activities, know what's happening in their locality and are socially active.

There are many ways of interpreting such preliminary data as shown above. However, such information can stimulate debate, a rethink and further research. The Register is a special sample. Some of these volunteers have never been in hospital or our out of work. Such people may rarely be studied.

Others are often in hospital or supported accommodation and have never worked. Perhaps these people are more likely to have been involved in schizophrenia research in the past and may give a specific view of the illness.

In any case, there appears a diversity of citizens within the Register sample. Citizens, who work, study, raise families and contribute to their community - sometimes all at the same time. They also have a diagnosis of schizophrenia.

Conclusion

The NISAD Schizophrenia Research Register provides a substantial pool of volunteers with schizophrenia for scientific research into the causes and treatment of schizophrenia. Additionally by examining the profiles of these volunteers a picture of a community sample has emerged that may stimulate further research and discussion.

By such activities NISAD hopes to foster a better understanding of this illness and its consequences for society. Census data from 2001 will soon become available for other comparisons. Further research into how people cope may also be forthcoming. Moreover, a better understanding of the diversity of people with schizophrenia may lead to a reduction in stigma.

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4.3   What is the Mental Health Information Service?

Linda Berrigan

Since its establishment in 1932, the Mental Health Association of NSW Inc has been at the forefront of efforts to provide good mental health and encourage early intervention and prevention of mental health problems.

The **Mental Health Information and Referral Service** assists consumers, carers, members of the general public, health workers, students, professionals, the private sector, media and government. The service maintains a comprehensive and accurate database of mental health support services in NSW and provides telephone and email-based information and referral. The Resource Centre, Friendship House, contains an information library and is available for informal meetings, training and education sessions and support groups. This paper will include:

- information on the services provided by the Mental Health Association of NSW;
- exploring ways we can improve our services; and
- inviting delegates to register their service on the MHIS database and their events
  or activities on the Mental Health Association Website.

4.4 People Like Us: the Issues and the Opportunities: What Works?

Leanne Pethick

In 1998, 83 people with depression and associated conditions and 25 family members from the corporate sector were interviewed to study the issues for people who do not consider themselves, or who are not "mental health consumers" from pre-diagnosis to ongoing management and treatment.

depressionet.com.au was established as an independent non commercial site in June 2000 to address, and provide solutions to, the issues identified by this research. Nine months later, and with no funding or financial support, *depressionet.com.au* became the number one ranking Australian internet health site.

This paper:

- presents the research findings ;
- explores the needs and demand that has driven this enormous growth;
- discusses the gaps existing between individuals and the help and support they need;   and
- identifies the opportunities to provide solutions.

Abstract

5.1 Resistance, Change Agency and Learning: What this might mean for the Consumer Movement (Mental Health)[3] and mental health services

Martyn Wilson, Senior Mental Health Promotion Officer, Western Sydney Area Health Service

Introduction

Psychiatry has a long history of isolation, control and containment be it by walls, drugs, fear, mythology, or the law (Porter, 1987). Over the last few decades these barriers have been falling. The Consumer Movement (Mental Health) (CM) is a part of this on-going change, yet there has been resistance. In this paper, I want to explore the nature of this resistance experienced by consumers from the mental health system including resistance by the Movement against modern psychiatric dogma and practice. We will then turn our attention to strategic action challenging and employing resistance. From my perspective as an educator, I would like to offer some possible avenues for exploration on how the Consumer Movement might make itself a learning movement, and how consumers can engage in further learning in order to decide on action.

On the environment in which the Consumer Movement arose: the beginnings of organised resistance.

In Western societies (and Australia is no exception) psychiatric services have acted as a state, institutionalised apparatus of isolation, control and treatment. In the past, this was evidenced by large institutions, invasive therapies (lobotomies, insulin-shock treatment, hydrotherapy etc.) and control through isolation and containment (Porter, 1987). More recently through drug treatment, community treatment orders and the various NSW Mental Health Acts. According to Foucault (1967), after the Enlightenment, secular ideas about the causation of madness[4] developed as a result of scientific theses. People experiencing a mental illness were confined in overcrowded asylums away from their communities with the poor, infirm, unemployed and retarded. This oppressive, coercive model of control, under the guise of scientific, medical treatment, worked to protect society; not treat the patient (Szasz, 1973). By isolating people with a mental illness in asylums, the medical profession responded to growing bourgeois condemnation of idleness and madness, while legitimising their own power as the dominant "reasoning" in society (Shorter, 1997). By labelling certain behaviours as madness, doctors could offer treatments for the protection of society while extending their power base. It could be argued that in Western cultures, madness has been constructed as a threat manifesting as a total absence of reason that only responds to medical treatment (Garton, 1988). White, middle class notions of normalcy, work ethic and family life had no place for abnormal behaviour attributed to mental illness. By the early twentieth century, there was a shift from the notion of asylum (read sanctuary) to medical treatment and care where the onus fell to the individual to reform and control themselves. From the 1980s, more sophisticated medications and a reduction in stand-alone hospital beds (Rozelle, Gladesville, Cumberland etc.) in favour of community treatment services shifted the burden of care from the state to the family.

Over the last decade, the voice of the consumer, so long silenced, started to rise. No more so was this done than by consumers themselves! Here the seeds of consumer resistance and CM started to germinate. However, as liberation in various guises started to unfold many staff in mental health services started to feel threatened by the new found strength and force of the consumers.

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[3] The appellation "Consumer Movement (Mental Health)" is my invention and therefore may not necessarily reflect the ideas of those consumers who represent the Consumer Movement.

[4] This word is used to highlight the context in which these original ideas about mental illness were formulated. It is no way intended as acceptable vernacular.

Consumers started voicing their opinions about:

- treatment practices;
- the nature of containment;
- the discrimination experienced within the mental health system; and
- from those who provide the service of care; the mental health professional (Plant and Hardy, 1994).

To my eyes, your Movement has found many ways to challenge the resistance and pretence within mental health services, and the health system at large, by offering resistance individually and as a social movement. For many staff (and services) this has been unwelcome and remains difficult for some to understand that the "patients" were having a say and have begun to affect change.

According to Shipp (1997), the broad aims of the CM are to:

- establish local Consumer Networks and positions within a variety of services;
- develop training opportunities for consumers and staff; and
- influence mental health service policy (Shipp, 1997).

The CM clearly articulates its vision for the future (network formations, forming real partnerships, paid advocacy, seeking accountability from governments regarding mental health) in a booklet entitled "From Consumer to Citizen …" (Shipp, 1997). It is argued that a fundamental social right is for people experiencing a mental illness to be treated in the same manner as all other citizens. There is now a growing social movement (the Consumer Movement) working towards redressing this breach of fundamental rights through social action. But how to achieve this effectively considering the resistance from mental health services and to some extent society remains a vexing question.

On the resistance faced by the Consumer Movement from mental health services.

The mental health system: hospitals, community health centres, the Mental Health Act, treatment regimes, and the various ideologies within psychiatry are a form of social control. Fear and misunderstanding about mental illness results in consumers being discriminated against during their illness, and long afterwards. People who have experienced a mental illness are one of the most discriminated and disenfranchised group(s) in our society (Plant & Hardy, 1994). I see on-going discrimination by mental health professionals as a form of resistance to changing circumstances where the consumer is gaining a strong voice, and is prepared to comment on and challenge those professionals. This resistance can come in many forms, for example:

- staff not acknowledging the consumer's experience of their illness;
- offering sedation instead of counselling;
- dismissing ideas of consumer representatives in meetings;
- mental health professionals attempting the redefine consumers as something other than they wish to be; or
- simply accepting that it is reasonable for the hospital staff rock band to be known as "The Secluders".

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According to Meagher (1995), there is a systemic view that consumers of mental health services have overwhelmingly negative characteristics including being unable to effectively conduct their lives, remaining a threat to society; being aggressive, unproductive, chaotic. In fact, these negative characteristics and consequent stereotyping have been so powerful that consumers of mental health services were totally ignored by broader disability action groups for decades (Behan, Killick & Whiteford, 1994). It has been suggested that negative stereotyping and low public and professional expectations need to be resisted and reversed through consumer and professional education, public re-education and consumer empowerment programs (Meagher, 1995). But, let us not place the consumer outside of the world of ideas in which they live; many consumers come to the system with negative ideas about mental illness and consumers. The dominant ideas about mental illness infiltrate one's thinking at an early age. This serves to erode confidence and an ability to see mental illness, consumers (themselves) and Movement in a positive light. This can form a type of internal resistance, which can be as strong as the resistance to change by many mental health professionals.

I would like to digress for a moment and talk about the subject of power. Power is a set of complex processes, and not everyone agrees on what it is and how it manifests. It would appear that power in this instance is centralised within the mental health system. However, Newman (1994) states that power can be scattered in a number of spaces and locations, i.e. decentralised. This idea gives some hope to social movements like the CM. In relation to this, Foucault insisted that power was not something one acquires, seizes or shares, but a complex flow and set of relations between groups which can change depending on circumstances and time (Ro... 1994). Foucault objected to the idea of our understandings and knowledge being outside of these networks of power relations. He was interested in how modern discourses shaped knowledge and power; some of these discourses have become 'regimes of truth' e.g. psychiatry, neo-liberalism, reconciliation, democracy, masculinity, femininity (Danaher, Schirato & Webb, 2000). For Foucault, power is something we live, rather than have (Appignanesi & Garrett, 1995). In contrast to this, Newman (1994) argues from a somewhat different point by suggesting power is essentially something we do have and can use to counter resistance to change, in favour of the oppressed. This power and resistance can also be experienced as the oppressed challenge established discourses and institutionalised state regimes.

Yet, between these two broad ideas, there is a tension here that we need to acknowledge and explore. Consumers need to be careful not to expend their power in a way that inadvertently reinforces the power of the state, especially if the CM is given and accepts some concessions to their demands by the system (Newman, 1999). Continuing, Newman (2000) suggests resistance needs to go all the way in order to negate the oppressor's power. This is a radical step indeed, akin to revolution. In our society, we can offer resistance against the state to varying degrees, but to proceed too far towards revolution may mean losing the support of the community. Members of the community may fear overthrowing (even metaphorically) state institutions and state institutional ideologies may be too extreme. The resulting backlash may come in the form of limited public support to possibly open condemnation or vilification. However, it must be remembered that the community discriminates against consumers less than staff associated with mental health services (Plant & Hardy, 1994). I believe broad public support is possible and will be essential to help redress resistance by the mental health system.
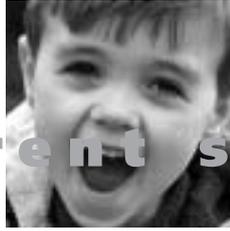
**On the Consumer Movement becoming a learning movement through resistance:
thought, dialogue, analysis**

I believe organised resistance could be developed through education. I explored two perspectives of learning (personal transformation and collective action through learning) throughout an interview with Jodie Brown earlier this year. Our discussion ranged from the resistance experienced from much mental health service staff, the resistance by consumers (individually, and as a social movement), and how the CM could develop into a learning movement.

As a consumer worker, Jodie has encountered some quite significant resistance from staff in mental health services. Resistance comes in the form of negative stereotyping of consumers, disrespect and a high level of obstructive behaviour from staff at all levels. This manifests in staff being unwilling to engage in problem solving with regards to negative attitudes, disrespect and dismissiveness experienced by many consumers. Although, it is Commonwealth and NSW Health Department's policy to have consumers on decision-making committees, many consumers find they are seen and not heard, not listened to, their ideas simply passed over or their presence simply not acknowledged.

When asked about the resistance consumers put up against the mental health system, Jodie initially responded by stating the CM was not strategically organised enough, which resulted in some uncoordinated resistance. But, she then went on to cite the constant lobbying for consumer rights, the publication of the book "From Consumer to Citizen ... "and using connections of influence on the fringes of the system (through the NSW CAG) to bring about change to policy and staff behaviour as forms of resistance. But, most importantly, I thought, was Jodie's statement that she was attempting to subvert the 'system' from within, from behind the "ramparts of the state". Once Jodie was able to undertake a personal transformation through learning, she was able to understand the various components of the mental health system and institutions as being sites of struggle and counter-resistance. As Gramsci suggested, Jodie and many in the CM are engaged in a "war of position" to resist against the dominance of psychiatric dogma (Newman, 2000). My point is that Jodie has come in behind the "walls" to become a player in the system working towards change through strategic resistance. Jodie felt the only way to address discrimination from staff (through their actions or uncritical engagement with the system) was to work on building up the strength of consumer representation from within.

Now, I would like to look at other ways that strategic resistance can be achieved. An effective way to resist is to seek out allies from within the system; that is, staff and other consumers and carers, who want to see things change. By forming allies who are prepared to talk or work behind the scenes, Jodie has found that she is not so isolated. These allies challenge discrimination within meetings, and constantly include consumers in discussions relating to all manner of activity undertaken by the mental health services. For Jodie, it was not enough to gain entry and then attempt to subvert the system in isolation. One needed the help of trusted allies who would work towards change with you and on behalf of the Movement. Of course, finding them in a conservative system can be quite a challenge, but one worth undertaking. Jodie felt that in order to achieve the goals set by herself as being an agent of change she needed external, supportive connections to debrief and rejuvenate because the system could be so oppressive at times. Jodie also knows there are certain things she

cannot say within the system, but can be said in other forums that may start to affect change through resistance. As complex as the notion of change agency is, sometimes change initiated outside of the system (but intended for it) can have a marked impact on the way the system works.

This three pronged approach of resistance:

- war of position;
- seeking out allies; and
- external action

can only take you so far. We need to be able to critically evaluate our learning from these opportunities.

The question remains, how can the CM become a learning movement? Social action informed by learning and analysis can form a strategic and effective resistance by consumers. Past mistakes and successes need to be analysed to develop new, effective strategies for action. Opposition needs to be proactive not reactive, and so adult educators have a role in planning strategies and facilitating learning within the Movement (Newman, 1999). Adult educators can help people become aware of the forces and controls preventing effective action. My point here is that through collective learning, new forms of resistance can be generated and trialed from an analysis of past learning and action. The educator has a strong role here, for he or she can become an ally in the struggle for consumers towards visibility, acceptance, change agency and citizenship.

With regards to mental health, Meagher (1995) acknowledges learning takes place on a number of levels; mental health service reform, and the breaking down of barriers through empowerment, involvement and partnership. Consumers will need to overcome a long history of disempowerment and develop many skills which require the group to act collectively to be able to play an effective part in planning, implementing and monitoring change (Meagher, 1995). One way this can be achieved is through reflective learning.

Jodie is an advocate for consumer-driven training programs and other strategies to achieve this end, and these would include the following points:

- skill development: assertion, stress management, report writing, meeting procedure;
- consumer input to others' learning needs: education for health professionals, media-based strategies, public education programs;
- rehabilitation for professionals: assisting health professionals to review current thinking and attitudes
- regarding treatment, consumer empowerment, partnership and learning the skills of listening; and
- assisting bureaucrats and decision-makers to consult with integrity with regards to the real human repercussions of the decisions (Meagher, 1995).

Another way learning can occur is for consumers (through the CM) to advocate for staff-consumer communication to be built into the organisational structure and (eventually) culture (Wadsworth & Epstein, 1998). The CM would need to remain focussed and continue to learn from past and present successes and failures, by fully understanding how the Movement works (i.e. themselves, their position and influence), the system, as well as through their learning. I agree with Wadsworth and Epstein's (1998) assertion that neutral

dialogue by an educator is fruitless, and that an educator needs to stimulate the learning group to look at other ways of seeing.

In her paper about unlocking mental health staff's energy and enthusiasm, Epstein (1997) suggests that telling stories to each other can free both the oppressed and oppressor. She argues this learning through sharing can lead to change as both groups begin to understand each other and work with the conflicts not always against them. Therefore I suggest this learning becomes a form of resistance against the oppressive ideologies and dogma of the mental health system. In addition, this is learning the CM can get involved with, and to my understanding, can become a forum for working through some of consumer-based learning strategies I have mentioned above.

Conclusion

In order to become a 'learning' social movement the CM must analyse past actions through various formal (e.g. courses, workshops) and informal (e.g. problem-solving discussions or meetings) learning opportunities. I have argued this learning is a key to constructive and effective on-going resistance against the oppressive ideologies and dogma of psychiatry. In my view, **the main form of resistance by consumers can be a result of effective learning towards strategic social action**. This learning needs to transfer to the collective and translate into social action through the Consumer Movement.

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5.2 Who's Really Learning?

Paula Hanlon and Laraine Toms

Northern Sydney Consumer Network and Carers Network in 1999 formed a partnership termed the "Consumer and Carers' Alliance." The aim of this alliance was to develop, implement and measure staff knowledge and acceptance of consumer and carer participation. Monthly half-day workshops have had successful outcomes with an identified change in staff knowledge and attitude. Another outcome or by-product of the partnership has been the learning and growth that has occurred for the educators including the development of facilitation and training skills. On a more personal level, is the learning that has occurred from understanding the issues from a carer or consumer perspective.

The presenters will share their personal experiences, suggesting that consumers and carers can work together towards common goals if there is an understanding and respect for each others' situation. *Abstract*

5.3 Consumer Participation in the Support Group Project

Gillian Church, Yvette Cotton, Nina Walton

The Support Group Project is a three-year project, initiated by the Mental Health Association NSW, with funding from the Northern Sydney Area Health Service. The aim of the support group project is to assist consumers, carers and workers set up and facilitate mental health support groups. This project has provided training for support group leaders, assisted with the establishment of new support groups and developed resources for groups such as a training kit and video.

The video: "Support Groups: A Guide to Setting Up and Facilitating Support Groups", was developed to promote the role of support groups and provide practical information for mental health consumers, carers and workers interested in establishing and facilitating a mental health support group.

It was produced in partnership with consumers who were trained and involved in all aspects of making the video including developing the script, filming, acting and editing. As a result, an informative, entertaining and "user friendly" video was produced with lots of insights, ideas and tips on how to set up and facilitate a support group.

The support group video project produced a much-needed resource to address the lack of support groups for people with a mental illness. It also provided an opportunity for consumers to share their knowledge and expertise, gain new skills and further develop their knowledge and skills in facilitating support groups.

Consumers have been an integral part of the project from day one. They have been involved in the project's Consumer Advisory Committee and Steering Committee. The Association and project have benefited enormously from the expertise of consumers while consumers have gained valuable skills and experience through their participation.

Collaboration between organisations and consumers can be a win/win situation for all involved.

Personal stories from Yvette Cotton and Nina Walton about their participation in the project.

Yvette Cotton

I volunteered to help with the video project because I thought it might be fun. It sure was fun! It was great to have something creative, productive and social to do that didn't cost us a cent. Consumers like myself participated in every stage of the video making from developing the dramatic sections though role plays, to acting and filming, sound recording and mixing, to interviewing and being interviewed and being case studies and also some editing. Kate Maclean the support group project officer was also involved in most stages and she and the staff from Art Resistance made us feel that our contribution was really substantial and valued.

I gained a lot from being involved in the support group video project. Every stage was enjoyable, but I particularly liked learning about the camera and filming techniques and also interviewing people. We got to hear the whole forty-minute interview not just the three minutes that each was cut down to. This enabled me as a support group leader to gain valuable insights into the workings of other groups. Script development through drama role-plays was great fun also. I enjoyed being the suicidal person in the script development. I found the whole video making process quite amazing. About ten hours of filming for a thirty minute video! The editing process was interesting to be involved in also. We got a say in what went in and what went out and how it was pieced together in what order.

So in this process we as consumers gained and the Mental Health Association also gained because of our expertise in having run or participated in a support group. As consumers we were able to keep the video on track and make sure it would be of use and relevant to other consumers. And the most exciting thing is being part of the production of a quality product.

Nina Walton

I am here today to talk about an endeavour close to my heart, the Support Group Project. The need for mental health support groups is unquestionable. A needs assessment carried out at the beginning of the project confirmed this belief. As a consumer and a facilitator of a group, I can personally vouch for their usefulness.

Consumers have been involved in all aspect of the project. When the project was without a worker for months, members of the consumer advisory committee filled in at the Association to ensure that the project kept rolling along. Newsletters, the work of different energetic consumers involved in the project have appeared regularly since the beginning of the project, keeping everyone interested and informed of our progress.

We believe the video is the jewel in the crown of this year's achievements. It was a very big undertaking. Our very special thanks go to John Reynolds of Art Resistance who produced the video. He made working and learning about video making a memorable experience. The video has a cast of thousands (well almost)— consumers, carers, health workers, educators. I hope you all buy the video and enjoy our contribution towards achieving better health outcomes.

Copies of the "Support Group Survival Kit" and video on "Setting Up and Facilitating Support Groups"
can be obtained from: Mental Health Association NSW
                          60–62 Victoria Rd Gladesville NSW 2111
                          Tel: (02) 9816 1611
                          Web: www.mentalhealth.asn.au

5.4 From Start to Stability: Rebuilding personal and community hope

Tony Humphrey

All the great things are simple, and many can be expressed in a single word: freedom; justice; honour; duty; mercy; hope. Churchill

My middle daughter Michelle suicided in 1985 at the age of 23. My eldest daughter said "dad, she didn't want to kill herself; she hoped she would be found! That's why it happened the way it did."

Did people notice how many times hope was mentioned yesterday? The Minister talked about *hope in Siberia … hope for the future … hope for opportunity*. Beverley Raphael talked about *capacity to mobilise hopefulness*. Arana Pearson spoke of it. Hope is that essential human characteristic still remaining even when life is flickering out.

> *Aliquam spem habere (Always have hope)*
>
> *the hope that leads us oft in dreams*
> *to yearn, to wish, to tread it seems*
> *on distant sand, or shore, or plateau high*
> *or reach and stretch beyond our earthly tie*
> *to fortune sad, or fate unkind: will*
> *if we strive but hard enough, reward us still*
> *with courage in our heart, to flourish and to fill*
> *our latter days with triumph over all past ill.*

Journey of hope: a brief history

I have been involved in mental health for more than twenty years in helping to build new dreams and aspirations:

- learning about and creating mental health information services;
- creating consumer and carer networks;
- developing community consultative mechanism; and
- creating organisations like, in 1991, the Australasian Association for Suicide Prevention (AASP).

In 1993, AASP merged with the National Youth Foundation to become Suicide Prevention Australia. In 1994 Suicide Prevention Australia had developed a great interest in research and education and less on real representation and support of people experiencing grief and loss from being occasionally, or frequently, or sporadically, or consistently suicidal. There was little suicide prevention, intervention and after support service, and mental health services were disappearing. The new mental health consumer movement was emerging to stake its place and consumer networks were becoming more visible. New consumer agencies with an ethos of sharing and support began to evolve and emerge.

A paradigm shift

Identifying people at risk is not enough. Today people with a mental illness are 300 times more likely to suicide (Dermot Casey). The proportion of suicides among known clients of the service in New South Wales **is the ultimate barometer of the system's ability to provide efficient quality services**. From 10% in 1995 this figure has now reached around 30% to 40% of the total in NSW an increase of 300% to 400%. The department will not confirm or deny this figure. Today the not-released Health Department's Strategic Plan shows the state has a shortage of over 800 non-acute beds.

There is an obvious need for a higher level of funding and a range of treatment options. It becomes more apparent when you see data showing that among mental health clients who suicide around 15% die on the same day of contact with a health professional, 50% within a week; and 90% within a month.

Experience informs actions

Personal experience stimulates personal action. Personal broad-spectrum experience contributes to constructive positive new-generation purpose. We gradually began to believe that even in the most emotionally damaged or disordered or illness state, it is possible to reconstruct damaged lives given sufficient resources and time. We believed it was, and remains, possible to return them to the enjoyment of life rather than the preoccupation with or resignation to despair and self-destruction.

In 1994 the existing paradigm of "suicide prevention" needed a rethink. The mental illness perspective and lack of effective services for people at risk after identification began to dominate intervention. Not much good identifying people without the services to treat them! We needed awareness of the increasing impact of drugs and consequent mental illness as well as the social contributors to desperation. Self-aided death is the sad (SAD) experience of many who will never be able to determine whether the person intended to die or not. It led to a rethink in terminology that could be relevant across the spectrum and so … "self-aided death (SAD)".

Best practice: evidenced based practice

Suicide is not simple. Academics struggle to find "best practice" and the bureaucracy wants to rely on "evidence-based" practice for which there is no evidence. There comes a realisation that no records, coronial or ABS, give and accurate picture of the size and ramifications of the problem, or its distinctiveness and relevance to Australia itself.

Principles of Service

"The greatest good for the greatest number" Jeremy Bentham

It could be said that a consumer network can provide all the answers. But do they? Consumer and carer networks have different needs and motivations and relate to each other only in a loose way and often see their needs as distinctly different. The challenge is to create a complementary interaction and association of interests.

Comparison of Action

Bureaucracy:

- is bound by policy that may be constrained by resources or driven by a hierarchical concept which can be indifferent or selective;
- policy can be stated and unstated and differently interpreted according to the vision of the individual and how that individual sees their place in achieving the vision;
- the vision of the bureaucracy driven by economic policy measures is of its very nature different to the vision of the organisation which is an individual entity motivated by the needs of its members and constituents.

The Networks

- networks bring together and allow independence of the individual yet unity of purpose;
- networks can be fluid and adjust to imposed policy or contest it, or resist it;
- the networks have individual consumer advocates at a local level.

The Incorporated NGO

- exists to represent the needs of its members and constituents;
- a consumer organisation has a charter that gives it legal and statutory positioning and a public face which can have the advantage of uncompromising integrity without taint or subservience;
- the agency is volunteer consumer driven against paid consumer driven;
- the agency can be independent and unaffected by pressures to be subservient to funding bodies;
- unlike a network which has a general vision from which it localises its aims, an NGO as an entity encompassing its broad church, must have a specific personal and direct uncompromising for and of itself;
- combines support for consumer and carer representation needs and can be an advocate for both;
- the terms partnership and working together have different meanings according to whichever side is "making with the rhetoric". To get the two to mesh is the ongoing challenge for an evolving NGO.

Working Together

Working together has different meanings to different people. Relatively it means overcoming prejudice and preciousness in the services and the companion agencies, the "we know best" and "this is our business" approach, and sharing information and service. It means we have to give up inappropriate attitudes if we are to be part of changing the culture.

Club SPERANZA: A philosophy of alliance and working together

- promoting and advancing the cause of other agencies and service providers dealing with suicide prevention, self-harm and self-aided-death (SAD);
- advocating for its constituents without favour;
- working in a positive and constructive way with service providers;
- promoting intergovernmental relations to advance prevention of suicide and self-aided death.

Our chief want in life is somebody who will make us do what we can Ralph Waldo Emerson

75

The New Interpretation: The beginning of Club SPERANZA

In 1994, Carol Jefferson was a Registered Nurse and mother who had lost her son, Cole, and who had lived through the experience over years, instead of months and days. Together we recognised that there was no specific "consumer" and advocacy organisation representing families with personal experience of suicide and self-harm. It could be a body that would advocate for all concerned about the issue, even though the idea of this being a group of "deserving" consumers was hard to get across. It would be a natural flow-on of the growing ethos of community and consumer caring and concern after the effects of suicide.

Returning to Churchill: The One Word Definition

Hopelessness can be an abiding characteristic. A one-word symbol was needed to promote the aims and the theme of recovery. The Association for Mental Health Suicide Consumer Advisory Group, which eventually became The Australian Mental Health Suicide Consumer Alliance or Club SPERANZA (meaning "hope" in Italian) was created. SPERANZA also stands for "Suicide Prevention Education Research Australia and New Zealand Action".

Advocacy: The Corporate Masthead

SPERANZA has recently taken part in what is believed to be the first ever mediation conference and process between the service and the family following a client suicide. This was undertaken with the mutual aim of assessing practices and procedures to modify and update protocols to mitigate the prospect of future system failures.

The SPERANZA "Hope" Centre

The "Hope" Centre will be the visible, identifiable and tangible administration office, call centre and resource centre for its two-part programme:

- IPSIS. An integral referral service for people at risk of suicide providing 24-hour counselling support through Lifeline and access to a variety of welfare groups, support mechanisms and therapy options via SPERANZA with prompt access, in crisis, to clinical mental health services;

- a complementary adjunctive programme of "Living Works" Applied Intervention Skills Training (ASIST) workshops for training allied health professionals.

The Centre gives SPERANZA the opportunity to take advantage of a greater range of existing and emerging technology and relationships.

The final reward: from the invisible to the visible … stability from visibility

When an organisation has to go it alone and take risks without the benefit of patronage, it builds its integrity in a much more powerful and confidence-building way. Each setback promotes further energy and greater strength.

NGOs that succeed tend to be those who are prepared to take risks and are persistent Narelle Kennedy CEO Australian Business Foundation

Stability and certainty can only come from assertive and confident action and the feeling of rewarded achievement. There is no greater reward than being able to see the remarkable improvement in people with renewed hope:

- no longer under threat of self-destruction;
- sharing a common aim and a common dream; and
- sharing the exhilaration of seeing dreams become reality in the individual or the body corporate.

This is what we mean by building personal and community hope.

A man named Wayne Gretzky made one of those self-evident but telling comments when he said "you miss 100% of the shots you never take!"

Tony Humphrey
Club SPERANZA
PO Box 96
NEUTRAL BAY NSW 2089

The SPERANZA Centre
162 Ben Boyd Road
NEUTRAL BAY NSW 2089

6.1 I'm Made to a High Standard

Desley Casey

A Festival on the National Standards for Mental Health was held on 7 October 2000. This Festival evolved from a Standards Workshop for NSW consumers hosted by the Northern Sydney Consumer Network in April 1999. At this workshop participants were asked to think of creative ways for consumers (and the community) to have increased awareness of the standards and how they can be implemented locally.

The idea for a Standards Festival came from Sandy Watson: a dedicated committee of consumers, carers and service providers brought Sandy's idea to reality. The Festival's theme I'm Made to A High Standard became the logo for fridge magnets, bags and stickers given to each participant.

A barbecue, skits, poetry, music, organisation stalls and a grand finale debate all contributed to the success of the day. This paper revisits the Festival and the presenter invites you to continue to celebrate the advent of the National Standards for Mental Health Services.

6.2 COAT Developing a Consumer Orientated Audit Tool for the National Standards for Mental Health Services

Douglas Holmes

This paper will provide some background information about the Consumer Orientated Audit Tool (COAT) currently under development as a management tool for implementing and assessing the National Standards for Mental Health Services

COAT has been developed in the Greater Murray Area Health Service (GMAHS). It builds on work undertaken by the Mental Health Consumer Advocacy Coordinator, as manager of the CANDO Project a three-year position funded under the 2nd National Mental Health Plan.

Two of the Key Performance Indicators for the Project were:

- to develop a quality plan with linkages into each of the nine (9) health networks and the 24 phone telephone service Accessline; and
- to assist with the successful implementation of the National Standards for Mental Health Services in particular Standards one (Rights) and three (Consumer and Carer Participation).

Development of COAT

COAT starts from the premise that the Standards are a minimum requirement. It is based on a simple scoring system to assess that a service has met, met in part or not met the Standards.

Scores are then converted into a percentage of achievement and graphed. This eliminates the multi-component nature of the Standards and provides a single number that can be not only used for trend analysis but also to compare the various elements and issues of the service.

COAT found a great deal of acceptance with people who have been shown the concept.

It is simple to use, increases consumer involvement, and is cost effective. It has also been seen as an effective step in the path leading to the external audit required by the Centre for Mental Health in June 2003.
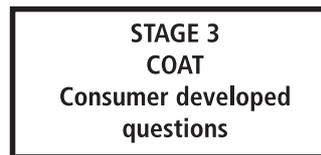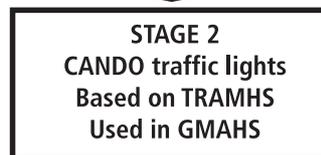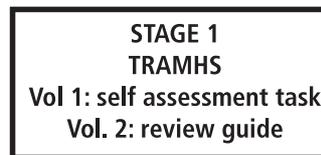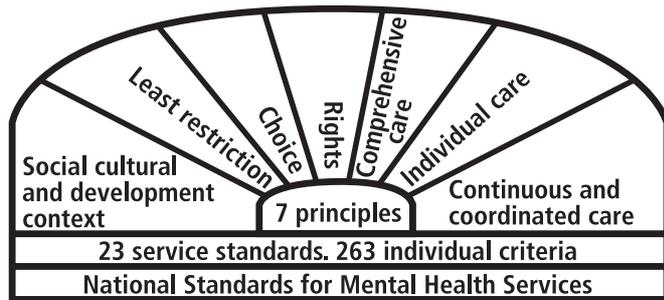
The principles for the model are guided by:

- The United Nations: Principles for the Protection of People with a Mental Illness and the Improvement of Mental Health Care: Principle 22 Monitoring and Remedies;
- Statement of Rights and Responsibilities;
- National Mental Health policy 1992;
- the report of the National Inquiry into the Human Rights of People with Mental Illness: Chapter 31 Accountability;
- the NSW CAG 1996 report "From Consumer to Citizen" that identified that an independent assessment of services along with the standards the system needs to be;
- more pro active and accountable than current mechanisms;
- developed in consultations with non government and consumer sectors and have the capacity to:
    - provide training and support
    - be responsive to local issues and identify systemic issues.

Development of COAT

Least restriction
Choice
Rights
Comprehensive care
Individual care

Social cultural and development context

7 principles

Continuous and coordinated care

23 service standards. 263 individual criteria
National Standards for Mental Health Services

STAGE 1
TRAMHS
Vol 1: self assessment task
Vol. 2: review guide

STAGE 2
CANDO traffic lights
Based on TRAMHS
Used in GMAHS

STAGE 3
COAT
Consumer developed questions

COAT
- Questions are in development
- 4 levels of attainment (high, good basic, poor)
- The COAT score is the sum of all the ratings
- COAT score give level of attainment

The objective of the Consumer Orientated Audit Tool (C.O.A.T.©) is:

- to implement an objective, consistent & effective Area-wide approach to the National Standards for Mental Health Services;
- to inform and consolidate the strengths identified and facilitate action strategies for the weakest areas;
- to document the increased understanding and concurrence that was achieved as a result of undertaking guided self-assessments of the N.S.M.H.S.;
- to collect information that becomes an input into the next stage of strategic development;
- to enable decision making within acceptable risk limits;
- to monitor the changes and impact of the implementation process.

COAT gives health services an indication of how their service matches up with the N.S.M.H.S.

COAT is one just one part of the **CANDO QI Cycle.**

The **CANDO QI Cycle** involves a six-step process:

1. Literature review: education and training
2. Self assessment
3. Complete Action plan
4. Implementation of Action plan
5. Review: self assessment
6. Revisit Step 1

The purpose of this system is to facilitate consumer and carer participation and staff engagement in Mental Health Service QI planning and delivery.
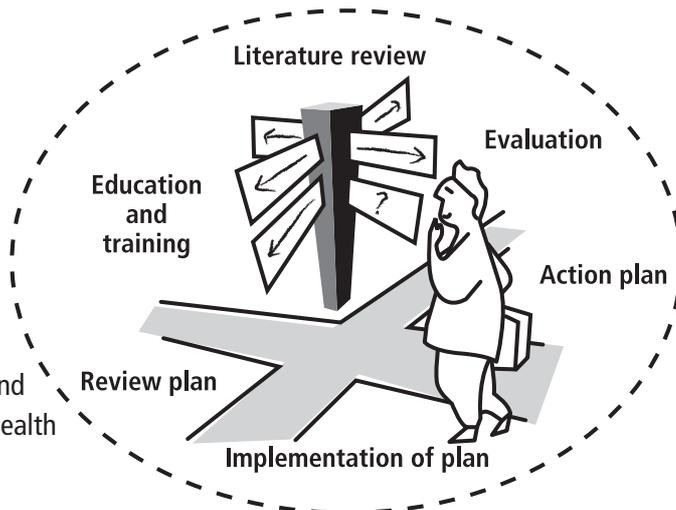
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Cooper, D and Jenkins A 2000. *Obtaining consumer feed back from clients of home-based care services*. Canberra: AIHW (Welfare Division Working Paper No 35)

Useful Internet Links

www.nswamh.org	NSW Association for Mental Health
www.amhcn.org.au	Australian Mental Health Consumer Network
www.mercury.org.au	The Mercury Centre
www.hcqualitycommission.gov	Health Care quality commissioner
www.amhcn.org	The Australian Mental Health Consumer Network
www.themhs.org	The Mental Health Services Conference

6.3 Gissing House Rights Booklet

Kylie Wilson

For the past three years I have been studying a Diploma in Community Services (Welfare) at Cootamundra TAFE. I am due to complete the course next year.

This course has a number of subjects designed to enable graduates to work in a number of welfare fields. Among these subjects are Mental Health Issues, Counselling 1 and 2, Interpersonal Skills, Programme Development, Working with Communities, Research, Child Protection, Drug and Alcohol Issues, Workplace Rights and Responsibilities, Policy Writing, Social Policy, Case Management and Assessing Community Needs.

All these subjects aim to give students the skills to interview, give information and support people in distress. Students also learn to develop their initiative and managerial skills together with their knowledge of the behavioural sciences. Students are also introduced to the processes of political and social change.

Due to my personal experiences in mental health, a great deal of my assignments and class work has been based on my experiences of living with, and dealing with, the mental health system.

As part of the requirements of the course I have to complete a 360 hour practical placement with an agency in the community service industry. I learned that the Greater Murray Area Health Service had employed a Mental Health Consumer Advocacy Worker. I contacted him to see if I could undertake my placement with him. He accepted.

As a result of my involvement with mental health services, I had identified many areas where changes and improvements could possibly be made. While I was not sure who I could approach with these suggestions, the placement gave me the opportunity to discuss these issues with the relevant people.

As part of the requirements of the placement I have to complete a number of tasks or a project agreed between the placement supervisor, the TAFE teacher and myself. These tasks, or the project, assist me to meet the learning objectives of the placement component of the course.

One of those tasks was my involvement in the updating of the Rights Booklet for Gissing House (Wagga Wagga), one of the acute care units in the Greater Murray Area Health Service. Over a three and a half year period I had had a number of admissions as a client to this unit.

The booklet, which is still in draft form, will include information on the unit including:

- meal times;
- general information about staff;
- times doctors visit the ward;
- visiting hours;
- programmes and activities;
- important phone numbers; and
- complaint contacts and procedures.

The booklet also contains information on what are the client's rights as a consumer of mental health services and explanation of the difference between a voluntary and an involuntary patient.

I plan to have diagrams throughout the booklet that are relevant to the information printed near them, so people who are having difficulty reading a great deal can identify what information is on the page without reading the whole booklet. For the same reason, the booklet will also have a table of contents. It will also be printed in large type so that people who have difficulties with their eyesight, possibly due to the effects of medication, will still be able to read it.

We have also discussed the possibility of designing an audiotape and video of the information in the booklet. This should mean that all clients will be able to access this information, without discriminating against those who can't read, see or hear.

I recently presented the first draft of the booklet at our area-wide Consumer Advisory Group meeting and had a great deal of positive feedback. I was given many ideas and suggestions on improvements and additional information that could be included. It was great to receive these ideas and suggestions because although I may be undertaking this project as part of my TAFE course, I'm still a client and the booklet is aimed at benefiting the clients in the Greater Murray Area Health Service. The booklet is for all clients and I would like as much input from other clients and staff as possible.

It's back to the computer with these new ideas and suggestions and to start work on the second draft, which I will then distribute for more comment and evaluation from clients and staff. I will continue this process until we come up with a booklet that we are all satisfied has the appropriate and relevant information.

If anyone has undertaken a similar project I would love to hear from you.

6.4 Triumph over Phobia and OCD: TOP

Linda Junee

TOP is modelled on TOP UK which has been operating very successfully in England since 1987. TOP's aim is to provide self-help treatment for people with panic/agoraphobia, social phobia, generalised anxiety disorder and obsessive compulsive disorder within a reasonable distance of the person's home. Leaders run structured self-exposure groups. People meet weekly in a group with a leader in a relaxed atmosphere of advice and encouragement. The person is shown how to confront their fear in a very structured step-by-step method.

7.1 Carer Advocacy

Elizabeth Ingram

My experience as a carer's advocate has taken me into new areas. Living with mental illness is not easy and I believe carers must seek education for their survival. For many years my two sons were non-compliant. Because I was in denial of the seriousness of their illness, I had no idea about schizophrenia and the diversities of the illness, the situation became quite unmanageable. Through information and education I recovered from my personal distress and started my climb to confidence. I became involved in criminal justice issues, organised forums on mental illness and received a grant to produce a carers' manual.

8.1 Australia's Young People: A Resource Rather Than A Problem Can Self-Help Support Groups Help Australian Young People?[1]

A research project of the University of Western Sydney and the NSW Association for Mental Health

Ann Dadich (a.dadich@uws.edu.au)

The mental health of Australia's young people has received increasing political attention in recent years. Recent Australian studies suggest:

- a quarter of all young people experience depression before the age of 18, with those between 15 and 17 years being most at risk (NH & MRC Quality of Care and Health Outcomes Committee, 1996);
- one in twenty 15 to 16 year olds engage in regular self-harm (Hibbert, Caust et al., 1996);
- 61 percent of tertiary students report suicidal ideation (Schweiter, Klayich et al., 1995);
- up to 11 per cent of high school students attempt suicide (Pearce and Martin, 1993);
- when compared with other nations, Australian adolescents have the highest usage rate of amphetamines by injection (Pennington, 1996); and
- young women have a harmful preoccupation with dieting, with 60 per cent engaging in unhealthy weight loss practices at any one time (Wertheim, Paxton et al., 1997).
- the suicide rate among those aged between 15 and 24 years peaked to the devastating figure of 446 in 1998, representing 25% of all deaths for this age bracket (ABS, 2000).

"We need an approach for dealing with these mammoth problems; one that will expand our resources without significantly increasing our costs" (Riessman and Carroll, 1995, ix). One such approach might be the use of self-help support groups (SHSGs), as their effectiveness and economic efficiency has been demonstrated repeatedly in the adult world (Lewis, 1988). These groups allow for a dramatic shift in perspective. Individuals requiring help become the providers of help; "we can view these people as potential help givers - a resource rather than a problem" (Riessman and Carroll 1995, ix, original italics).

[1] This paper is derived from an article published in Network: the official publication of the APSCollege of Community Psychologists.

Whilst the conditions around which SHSGs form may be diverse, they often share common characteristics. These include:

- commonality of problem (Madara, 1999);
- participants relate to each other as peers (Kurtz 1997);
- participants can be both **helper** and **helpee** (Gartner and Riessman, 1977; Levine and Perkins, 1987); and
- control of the group remains in the hands of group participants - it is they who determine their needs, their wants, how best to provide for these (Thorman, 1987).
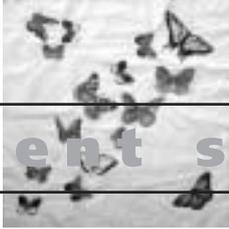
The literature identifies several benefits from involvement in SHSGs, particularly in those groups that address mental health issues. Richardson (1983) has identified increased access to emotional support; the provision of information and advice to ease the coping process; access to direct services which can be provided casually or through a structured format; opportunities to become involved in social activities; and the initiation of societal change through lobbying initiatives. These groups can also offer opportunities to further develop the social and organisational skills of participants.

Adolescence is often a time that psychological disorders have their onset with around 50% first being manifest between the ages of 16 and 18 years (Sawyer, Sarris et al., 1990). Depression, substance abuse, conduct disorder and psychosis have all been cited, with suicide, psychosis and the effects of abuse perceived as having the worst prognosis (Sawyer, Meldrum et al., 1992). It is estimated that up to 15% of those aged under 18 years suffer from psychiatric disorders, which warrant recognition, and up to 5% that suffer from disorders, which warrant intervention (RANZCP, 1984). In New South Wales alone, there are approximately 1.25 million people aged between 12 and 24 years; 20% of the population (NSW Health, 1998). This fact should mean an abundance of appropriate treatment options. But often difficulties in diagnosis are accompanied by difficulties in treatment. This is further impacted by the stigma often attached to mental illness (Boss, Edwards et al., 1995)

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A support option for young people that requires further consideration is the SHSG. Being less formalised and economically accessible, these groups might be more attractive to young people experiencing mental health issues. Furthermore these groups can be an adjunct to formalised treatment options.

An exploratory study is currently underway to investigate the experiences of Australian young people in SHSGs. Young people who have experienced a mental health issue and have accessed a SHSG were interviewed to determine whether they believe their involvement was helpful or worthwhile. Although barriers were identified that prevented their access to the SHSG (namely, denial following initial diagnosis and the lack of other young SHSG members), tentative findings suggest several benefits of group involvement. These include:

- an awareness of similar others;
- hope from older members;
- practical coping strategies;
- reduced social isolation;
- increased confidence and esteem; and
- an altered relationship with service providers.

Further analysis of the interview material will be conducted to explore these experiences in detail. These findings will then become available in the hope of influencing social policy and raising public awareness (particularly among young people and youth service providers) about the potential benefits of involvement in a SHSG for young people experiencing mental health issues.

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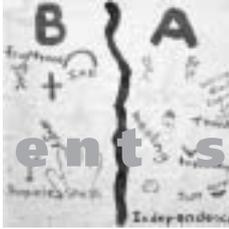
8.2 The REDDI Project

David Whealing

The REDDI project is a prevention program. REDDI is **R**eacting **E**arly for **D**ual **D**iagnosis **I**ntervention. REDDI is attempting to look for risk factors likely to be associated with adolescents who are at risk of sliding into a mental illness and concurrent substance abuse. Such co-morbidity is often termed a dual diagnosis. REDDI is particularly interested in promoting the role of community agencies and significant others to improve their interaction with adolescents who are "at risk" of sliding into a dual diagnosis.

The REDDI program commenced in the year 2000. Hence the REDDI is at present (2001) exploring a number of the issues associated with the expression of co-morbidity in adolescents. These avenues include:

- extensive literature review,
- an extensive case note review,
- a survey of community agencies, and
- interviewing a number of adults with the co-morbidity on factors associated with their adolescent history.

The project is too new to have yet developed strategies for implementation. Prevention programs in mental health are very embryonic, and we are not quiet REDDI yet. Inclusion of mental health consumers in developing a name for the project has been a good way of keeping the project at a grass roots level. Active consultation with mental health, and drug and alcohol service providers is continuing. Active consultation with community agencies dealing with adolescents has been well received.

I would suggest we need to invest and build social capital for mental health. I would argue that the social determinants such as the networks, the trusted friends, and actual shared community norms in perceived communities, need repair and, in some cases, replacement.

The use of social capital, requires the building up of community capacity. This is the strengthening of communities by ensuring that people are better informed of knowledge which enable community participation for better health. **This then, is one role prevention programs have in beginning to put a limit to mental illness.** Such mental illness prevention has some unique characteristics that differentiate it from how treatment issues are currently perceived. For example, prevention will be about issues applicable to groups or particular selected populations, while treatment is currently about the individual. This is a major mind change for most MH workers.

Secondly, this prevention, via community capacity building is currently at odds with some adolescent's values. For example "Individuality" has become a perverted concept of selfishness that "scotch-guards" the teenager from the information at hand. The cost of prevention "preaching" to such a group, and the teenager seeking only the "individualistic" message, will come at the high price of the familiar incommunicado between generations. So there is a need for adolescents to appreciate that there is still some learning to be done. At the same time community capacity building will require some rethinks on how to best obtain sensitivity to translate information to become relevant forms of knowledge for adolescents and teenagers.

From the esoteric to the practical. How is mental illness and substance use "prevention" going to make its way to the most needed? Vis a vis the not so bright, the low self esteem, the traumatised, sexually abused, and socially isolated teenager?

9.1 Healing Tears

Linette Bone

"They" think I am unwell I cry. "They" think I am unwell if I don't display emotion!! Result: One consumer writes a book about her experiences, beliefs and needs surrounding mental illness: Healing Tears. Come and chuckle. Raise the comradely fist and weep a silent tear.

Hospitals Aren't Necessarily Places of Healing

In the smoky clothes-sodden wards
of the hospital's psychiatric facility
there are unwritten laws.

If you can't identify
With the 'tough' puffing
denizen of residents, keep clear–
their pain resounds to a different refrain.

Between the knowers and the staff
they sort out cigarette sharers,
the clothes carers, the tolerance wearers,
the health bearers …

Times change and theories range, still the
fine line between deviation, delinquency and disorder …

The "attend to prove well or at least ask for help"
morning patients' meeting–
shambles of disempowerment like our minds.

The woman in the bed next to me
pulled the curtains to hide
her wrists freshly slashed.
"I've done it again, Sister"
Scary, sitting squashing myself
into pillows to allow her preferred secrecy …

Caught in any silent dawn bird-feeding ceremony
By artist younger and surer?
As I fed the magpies yesterday's bread,
tears of incomprehension
sobbed down my cheeks;
a friend, a resident of previous time,
had burnt to death in her lonely two-bedroom flat.
An accident, I believe.

Younger girl held me, crooned as I cried.
It didn't matter, she didn't know why.
Hearts know.

Positive Psychiatry

Hearing with empathy
my tale of psychiatrist rape
and not diagnosing me as delusional …

Attending my book launch
and lining up to request
my autograph …

Offering to lend me
his copy of Wounded Healers
acknowledging my professional self …

Recognising my need for sorrow,
seeing tears as the seeds
for healing words …

Sharing his family sniffles.
Strengthening my faith
in my own humanity.

Letting compassion
clearly shine
in her eyes …

Allowing me to choose
what to reveal
of my previous history.

Working together
to fight
the tardive dyskinesia …

I Think I Hide It

I have had a disability for over twenty-three years.
I rarely admit it.
I think I'm fortunate
to hide it, remain anonymous
At least I think I hide it.

I know even with medication
I have to discipline my own mind talk
"Was that a voice
or merely my own foldback?"

Sometimes I confuse concepts
even when teaching in front of a class;
other times my tongue swirls the wrong way;
and I've been to the cinema
when my whole arms refused to sit by my side,
became windmills outside my control.

Mostly I hide my disability.
At least I think I do.

When major disturbances occur,
like neighbours threatening to get a gun and shoot—
he'd never even met me—
people didn't ask "How are you?"
They asked "Have you taken your medication?"

But I'm normal.
At least I think I am.

That's not totally untrue
I've never felt normal.
All my life I've wondered
"How do normal people think?"

I've even prided myself
on not being boringly normal
and cultivated difference.

Really is anybody normal?

I think I hide my disability...
but inside, in my heart,
the joy is just as fresh,
the love is just as passionate.
Is the disability I hide
Inside my mind or theirs?

Peter and the Bird

We sit in a meeting
as if in a preordained pattern,
consumers one side of the table,
providers on the other side
For just one minute stop and really watch…

Peter sees the eyes are on the papers,
not him,
when he speaks;
inside he's hurting,
deeper inside there's
a resilience born of days and nights

of no light, of no meaning.
He leans forward.
There's an urgency in his voice.
"I've just got to communicate this meaning to you."

A quizzical glance, an intellectual frown;
and with his spirit he spins the image and metaphor
of wounded bird
needing to fly.

We have laws for allowing nature to heal.
We respect nature.
Peter achieves the miracle
of one soul shining.
We learn.

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Extracted from **Healing Tears**, Ginninderra Press, Canberra. Linette Bone (2001).

9.2 COW: Consumer Organised Work Cooperative Developing a Consumer Cooperative for Consumers by Consumers

Peter Gates

The COW Cooperative Working Group has been working for over a year and the Cooperative will soon be registered. Assisting the working group as business adviser is The Mercury Centre Cooperative Limited, a business resource organisation whose role in life is to support people that build communities.

COW Cooperative is about consumers and providing opportunities for work in all its forms, at the same time serving a need in the Mental Health Services area.

The COW Cooperative will be registered under the Cooperatives Act 1997 (NSW). COW comes from **C**onsumer **O**rganised **W**ork. The concept is simple yet powerful. Consumers working together to achieve a better life through meaningful work.

A cooperative is defined as "An enterprise freely established that is owned and controlled by a group of legal persons for the purpose of equitably providing themselves with mutual benefits that arise from the activities of the enterprise and not primarily from investment in it". (Plunkett Foundation, UK).

The cooperative will be a legal entity, owned and controlled by the members with a board of directors elected by the members on a one member one vote basis. It will be a business enterprise focussed on self-help.

Consumers will own the cooperative, through buying shares in it, and control it through general meetings and elections for the board of directors. They become members of the cooperative, and used effectively, the membership can be very powerful. The strength of the cooperative will be the member/owners. The many working groups required for the myriad of activities will come from the membership as the volunteer nature of the cooperative will be strong because they are consumers. The business structure can be adapted to the many needs of the consumer community. A members committee at Orange can sit comfortable beside a business division in Parramatta. The internal controls can be matched with the needs of consumers.

The five major streams of the cooperative are the development and support of business opportunities, the creation of profit generating enterprise centres, the provision of consumer friendly training services, consultancy services to government & business on MHS projects, and business opportunities that create better health outcomes for consumers.

1. Business Development is about the development of new businesses for consumers in whatever form that is appropriate for them. Included in this stream are:

- **Business Support** which is the provision of advice on all aspects of business start-up to the point where the business is functioning fully. The time frame for this support would be in the order of five years.

The two streams of business support are:

Commencement: the structure of the enterprise: cooperative, company, partnership etc, business planning, registration, funding, and other startup issues

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Maintenance: business education, marketing, financial management, compliance with regulation, mentoring

2. Business Initiation

This is active intervention to seek out

Business Initiatives: identification of concepts suitable for consumers;
Resource Matching: putting ideas, skills, capital, property and people together to create opportunities;
Venture Capital: development over time of funds and funding sources for consumer business.

3. Advocacy in Business

This is the:

Issue Identification of matters affecting the development of consumer based businesses in government legislation, regulation & policy, business and community attitude;
Engagement with government, business and the community to create a more consumer business friendly environment;
Showcase successful consumer businesses.

4. Enterprise Centres is the development of enterprises that will be profit centres for the cooperative where there is a viable business but the infrastructure is not currently available within the consumer community.

5. Employment Services is the provision of various services around employment such as a job bank, assistance with job applications (database of previous learning and resumes), and employment preparation (job interview training and personal presentation advice).

6. Training Services is provision of training services, as a Registered Training Organisation, that is consumer friendly and uses consumer specific adult learning techniques, and specially aimed at the National Standards for Mental Health Services in the areas of Standard 3.3 and Standard 9.17.

7. MHS Consultancy is the provision of consumer based Mental Health Services consultancy to government and private industry in such areas as disability planning, mental illness awareness training, and mental health specific special needs projects.

8. Better Health is adopting a business approach to a range of projects to promote better health for consumers. By creating business opportunities from a range of projects to promote better health for consumers, employment can be generated.

Planning for the Cooperative is well advanced. A Strategic Plan has been developed as have a number of project proposals.

Two projects are detailed here being COW College and COW Travel.

COW College is to develop a range of learning focussed mostly on work skills using existing programs and packages with some new ones to be developed based on need. The focus will be on delivery of services when and how it is wanted. Part of the project will be the development of a central database for recording and
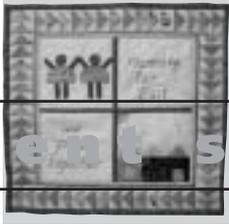
keeping learning achievements with the records available printed out for job applications. It is expected that a job application service will develop over time as well as a number of other employment related activities.

COW Travel has two aims: to allow consumers to have a holiday and to provide employment for other people to help them have a holiday.

The concept begins with the design by consumers of a suitable package for a holiday in their local area. Documented and pre-tested to make it appropriate for consumers and their needs, the package will be at the right price and the right pace. It will detail how to get there, where to stay, and what you can do when you get there The package will also identify a range of matters from where to get good food at a reasonable price to where to go to replace lost medication.

This package will then be marketed by COW Travel to consumers in other areas with COW Travel being the bridge between the traveller and the holiday. Part of the payment for the holiday will go to the people involved in the design and running of the holiday.

The types of travel will range from do-it-yourself to guided tours for individuals, groups and families. Some of the ideas suggested have been beach side towns, farm stays, sporting trips such as ten pin bowling competitions or learning to do a sport, educational tours, tourist tours to major cities and a study tour and workshop in New Zealand.

The necessary papers for approval of the Cooperative have almost been completed with the interim board selected. It is expected that the cooperative will be registered by January with people able to join shortly after that. To join you will need to complete a membership form and pay the annual subscription of $10.

9.3 Consumers in the Arts (CITA)

Lynda Hennessy

CITA is a group of consumers who are also artists who want to create art in their community. We have been helped and encouraged by the COW Co-operative, who are organising meetings at the Coffee Shop near Accessible Arts on the second Saturday of each month. In our first workshop we had a Dream Workshop: some of the wishes were:

- to express creativity and offer healing and hope;
- to be self sufficient in my aloneness; and
- to work constructively and engagedly in projects that involve joy as much as any other endeavour.

The four projects we want to work on are:

- video a documentary or play;
- write a book of consumers humorous experiences when psychotic;
- produce a CD of music and poetry; and
- art workshops.

session 10 participation and advocacy

10.1 We Need Strong Consumer Advocacy, Now and in the Future

Suzy Stevens

In New Zealand people who are treated by mental health services have very few rights. Our mental health law removes the right to refuse treatment. We have to know what our rights are and have the power to ensure they are upheld. This can be extremely difficult when under the influence of prescribed drugs.

One of the ways we can hold onto the few rights we have is to improve the availability of consumer advocacy. This type of peer advocacy is provided by consumers and is about working with people to try to obtain the best possible outcome for them. It is driven by the person, for the person and the advocate is the conduit for information and opinion.

The presentation outlined a brief history of consumer advocacy in New Zealand, some information on what it is and how it works. It also described how important consumer advocacy is now and in the future to ensure our rights are adhered to and that we get the best possible service/s when we are being treated by mental health services.

10.2 You Get Splinters Sitting on the Fence

Maggie Lawson

This paper reflected on aspects of participation and on the Consumer and Community Participation (DOH) Report. It examined the values that might underpin such a process and how it might become an effective way to develop a women's health consultation group.

## 10.3 Grass Roots and the Pure Consumer Perspective

Gary Platz

This presentation discussed the value of the grass roots volunteer sector and its importance in keeping the 'consumer view point' pure. It also discussed the need for paid consumer workers in specialist consumer positions to stay close to the grass roots.

10.4 Establishing CAG in Griffith

Margaret Mortlock

When a person suffers from a mental illness, it is the most degrading of all illnesses: one loses self-esteem, self-worth and suffers self-doubt. It is during this phase of the illness that one needs someone to care for you, or a group to support you and to advocate on your behalf for better treatment and services to make what seems so right to the consumer to be positive in the eyes of the carer.

Not all consumers have a family member as a carer or have someone to advocate on their behalf when the need arises. Consumers and carers saw the need for such a group in our area. With the assistance of many support services in our community, the Griffith Mental Health CAG became a reality on 24 February 1999 after the Greater Murray Area Health Service (GMAHS) initiated a forum in January that year.
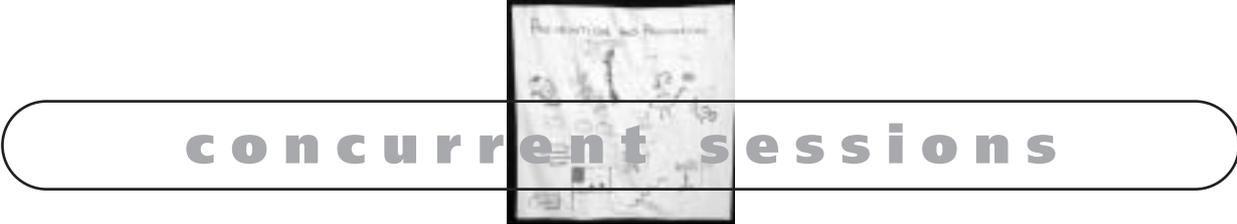
Prior to the formation of our group, it was the dream of Tim Daley, our team leader, my mother Cecilie Mortlock and myself to reduce the stigma that surrounds mental illness. We were keen that consumers could be accepted into the community as worthwhile citizens and to show the community that one can regain what one has lost after an episode.

With the support of our ARAFMI Branch and other consumers, we attended conferences and addressed the GMAHS team leaders and community managers on the needs of mental health consumers and carers. Even though my mother and I spoke openly, clearly and bluntly about the issues in our community, we found it can be a lonely road. We found that people will support you in private, pat you on the back and tell you what a good job you are doing by publicly voicing your concerns, whist publicly they will reject you. It is only by changing the attitudes of the community that one can reduce the stigma that surrounds mental illness.

As you are all aware, one person in five will suffer a mental illness at some stage of their life. It is imperative that all communities begin to encourage, support and accept the consumer as a whole person so that they may regain their self-confidence and their self-worth after an episode. These people should be able to walk down the street with the pride of who they once were, who they are now and who they can be in the future with acceptance from the community that mental illness is an illness like any other illness.

Prior to the formation of our group, it took many phone calls to Lyn Hamilton, our Community Health Manager and Wayne Hurley, the Program Manager of the GMAHS Mental Health Service. We had so many phone calls and spent hours discussing our needs that we could only wonder what could ever be achieved by even contacting them. It seemed we were on a merry go round getting nowhere.

We contacted and sent numerous letters to various dignitaries including the Hon Craig Knowles, NSW Minister for Health, Karen Peake, CEO of the GMAHS, Adrian Piccoli MP, State Member for Murrumbidgee, Kay Hull MP, our Federal Member of Parliament and other community organisations - with the results seeming to be proactive. The members of our steering committee felt we were floundering and getting nowhere so we came up with the idea that sometimes you have to upset the applecart to get things moving even if we were not politically correct most of the time. We lobbied in a subtle way hoping to achieve a positive outcome for the service. We maintained that in order to achieve a positive outcome we had to work together as a team. Working in partnership with Griffith ARAFMI, the service providers in our area, the community in which we lived and abroad. Even if it meant we had to step on a few toes along the way.

Our Steering Committee participated in and was the driving force behind the Mental Health Strategic Planning meeting for Network 1 on 28 June 2000. At that meeting we were able to discuss openly our hopes and dreams. The needs of our community, consumers and carers were discussed and, as a result, a wish list created. We worked together discussing our hopes and dreams and found that our hopes and dreams were the same hopes and dreams as everyone present.

Our wish list became a reality. Nothing comes easily, but we discovered that when we work together we can achieve our hopes and dreams. We came away from that day feeling positive that we were representing the whole community at large. We felt part of a team with common needs and ideas to achieve a positive outcome.

We have worked together to attain some of those dreams and are still working on others. We have all learned that by working together we can get better services for consumers and carers. We have come a long way in our area in achieving some of those needs on our wish list. We have lobbied and petitioned the services and the community for support. We have also participated in fundraising to achieve some of those dreams. As a result we have regained our living skills and rehabilitation service, with separate offices provided for both CAG and ARAFMI "free of charge." This resource centre has been supported by the GMAHS and has become an important part of one's recovery by offering support, friendship, education and information to consumers and carers.

We have seen consumers come and go through the group. We have had carers supporting consumers in their office bearer positions, as the pressure of those positions required the consumer to take a break. This works well as one sees that the consumer with the support of a carer can take an important and active role in decision making.

The community has supported fundraising with business houses donating goods and services to raise funds for running costs and the incorporation of the group. Meeting times have swapped and changed, but the new date and time decided by the consumers has proved positive, with new members participating in input. We have had sausage sizzles and street displays, all supported by the Rehabilitation Service, ARAFMI and CAG. We have worked on other committees such as Suicide Support, Town and Country Gay and Lesbian Movement, P Flag and church groups.

We have worked side by side with ARAFMI in their school education programme in its organisation and delivery as presenters in the classroom, giving our testimonials to the students, parents and teachers. Drawing on our personal experiences we have helped to educate them on where to access help, services, information and referral with the hope that this will decrease the stigma within the community as well as helping others access services. We have been interviewed by the television, radio and newspapers in order to raise awareness, to reduce stigma and to promote access to counselling and other services, including help lines.

I would like to share this poem I wrote for today. I know I am plagiarising our advocacy coordinator Doug Holmes' motto CANDO.

I Can Do It

I Know

I can love

I can laugh

I can feel

I can breathe

I can share

I can see

I can care

I can be what I want to be

I can say, do, dream

We can do

We can advocate for the weak

Be a friend to the strong

We can be an ear to listen to all those in between

We can convey, enhance, fight, support, unite

And see what we all can be,

Just be We.

Margie Mortlock

10.5 When Tea and Sympathy is not Enough: Mutual Support and Mental Health Service Reform

The role of the support group for consumers and carers of people with a mental illness in providing a safe, caring environment for mutual support and sharing of experience is clear. This role is invaluable in validating the individual carer's or consumer's experience: in 'normalising' to a degree the patterns of life and daily experience that, while everyday to the consumer or carer, can be shocking and unbelievable to others. The support group provides a forum for sharing such experiences and even finding humour in them. The culture that is shared by people living with mental illness in the family transcends usual socio economic, and ethnic boundaries. For carers and consumers there is instant recognition, identification and supportive friendship. This is not always true of the interaction of consumers and carers—a relationship which is often, but not always, fraught with conflict and difficulty.

The support group can also provide education and information and often does. It can provide access to outside expert speakers. But too often, I would suggest, with respect, carers groups (and I can only speak for carers groups as I am a carer) don't provide a way forward in the carers journey to acceptance of the hand that life has dealt them and the one they love, and to meaning in the life that is left to them. And I don't mean some sentimentalised saccharine platitude that is so often offered to carers – you know the kind – 'God must have chosen you because you're so strong and can handle it' – or the one that floored me once –'You must have reached some higher state of insight because of the suffering your family has endured' – '… bugger insight, give me sleep' was my response.

Sentimentalising maintains exploitation

As we know there is courage and fortitude to be found in consumers and carers. For carers there is also exhaustion and despair. Sentimentalising the lives of carers is just another way of justifying the continued exploitation that has led to carers providing not just peripheral support of the mental health services but the foundations and the infrastructure, the labour force, both clinical and practical and because they are not paid (except for the pathetic carer's allowance or pension) they provide huge cost savings as well.

And carers wear this exploitation. Many are too tired to think of there being any other way. Many are too guilty. Parents of children with mental illness redefine parental guilt. Most are unaware of the rights, however limited, carers have under the second mental health plan and National Standards for Mental Health Services. Many are unaware of how to go about achieving change or the benefits that such action could bring to them and the wider carer community. Carers have a long way to go before they catch up with consumers in getting organised and active.

All carers know the anger that is simmers just below the surface. The anger about the way they and their family member are treated in hospital or the community health service, the anger about lack of services, stigma, discrimination.

Get angry, then get active

Anger is destructive. It contributes to the ill health, both mental and physical, that carers live with. But anger that is converted to activity, to advocacy, has positive benefits for carers and the system as a whole. In a life where the central feeling is that of not being in control, of always being tossed around by a whirlwind, never knowing what that day, or night, could bring advocacy can restore a sense of meaning and purpose. It has structure, goals, shared purpose and outcomes to bring a sense of real achievement, even while still knowing that one's own family member might not directly benefit immediately.

There is no doubt tea and sympathy are important. But they are not enough. They can take a carer only so far in their life journey. When not combined, at appropriate times, with opportunities for growth, and I suggest advocacy is one such opportunity, tea and sympathy can in fact lead to stagnation and a sense of helplessness, a feeling that one is powerless.

But advocacy, whether self or systemic, is too hard on your own. And here is where the support group can take on another, complementary role to the care and share, tea and sympathy model.

Not all support groups will want to take on advocacy. New groups for example will still be needing to get to know and trust one another. The tea and sympathy model is still appropriate for them. But with guidance, and here I suggest is an opportunity for the group leader, the group can be introduced to concepts of advocacy and make decisions about what, if any, advocacy is right for them.

Advocacy Decisions

The journey to effective advocacy

> **Step 1. A little, a lot or none at all – how to decide? Consider:**
>
> > a. what does the group understand about the meaning of advocacy?
> > b. group readiness for advocacy – how would you determine this?
> > c. group consensus – what would you do if some are interested and some are not?
> > d. what goals – how would you determine these?
> > e. given that not all advocacy will succeed how strong is the group?
>
> **Step 2. Once the decision to take on advocacy, no matter how much or how little, has been made the following should be considered:**
>
> > a. What **resources** does the group have? One of the keys to effective advocacy is **knowledge** – of self, (what I call the self audit – why do I want to get involved in advocacy – how resilient am I, can I leave emotion at home, can I be objective?) knowledge of the system, levels of decision making, relevant state and federal policy documents, knowledge of existing groups with common goals, peak bodies both state and federal. This means a resource base of some kind – a small library. The Kit. Government publications and how to access them. Knowledge of what contributes to effective advocacy and what the barriers to effective advocacy are. A workshop on this can provide a very stimulating group session.

Let's simulate a group session on this now.

b. **What structure?** Sub committees for media watch, local issues, selection for reps on local, state and federal workshops, committees or whole group involved? Who will take responsibility for what? Who will support reps with debriefing? Is there a system for reporting back to the group on representative activities?

c. **Rights and responsibilities as carers** – is there an area policy? If not, develop one. Often the foundation for effective local area advocacy.

d. **Rights and responsibilities as carer reps** – is there an Area policy? If not, develop one.

e. **Ethics**. Being accountable and responsible. Has the group developed a code of conduct?

f. What **skills** are needed? Internet skills? Presentation skills? Basic computer skills? Interpersonal communication skills? Conflict resolution skills? Negotiation skills? Just developing a skills needed list and developing a strategy for developing these skills is a very positive activity and can lead to significant personal growth.

Step 3

Active Advocacy: Getting out there and doing it!

Step 4

Ongoing review and evaluation: The group needs to ask itself regularly whether the advocacy activities undertaken are right for the group – too much or too little? Too few people taking too many rep roles? What has been achieved? What has failed and can reasons for the setback be identified?

Remember that advocacy is not only about systemic change. Advocacy is a continual reminder about the things that really matter: respect for the individual, basic human rights for all, hope for consumers and carers.

From Consumer to Citizen Revisited

Paula Hanlon, convenor "Consumer to Citizen Revisited"

NSW CAG has begun a process of reviewing the document "From Consumer to Citizen" (1996). This document, produced by NSW CAG was developed from a Consumer and Community forum held on the 26th August 1996. It highlighted ten significant themes or issues as identified by the 100 people who attended the 36 workshops. These issues are:

1. Standards
2. Training needs
3. Consumer positions and networks
4. Independent assessment of services
5. Guidelines/payments
6. Partnership
7. Clarification of government responsibilities
8. Paid advocacy
9. Respite
10. Consumers from non-English speaking background, aging, Aboriginal and Torres Strait islanders, gay and lesbian consumers, multiple disabilities and other groups

A summary of these issues from "Consumer to Citizen" is available in each satchel.

The NSW CAG formed a subcommittee consisting of members and associate members. This group reviewed a number of State and National Policy documents to identify directions suggested, planned and those implemented from the above ten issues.

Throughout the conference, there were opportunities for people to participate in the review of these and any other issues. Delegates were asked to identify the issues from the above ten that they considered the most important. There were also be opportunities for people to list additional issues.

On Saturday 10 November, delegates workshopped these issues by addressing two questions:

1. What is happening in your areas in regards to these issues?
2. What should happen in the future?

While in these groups participants were asked to complete two surveys. The first provided demographic details (e.g. gender, age group, area you live in etc). The other gathered data addressing each of the ten issues from "Consumer to Citizen" (1996).

Following the consultation process at the conference delegates were advised of further opportunities to discuss issues with CAG members.

The subcommittee will develop a draft revision document that will be available for comment before publication. Once published the document will provide a summary of the NSW Consumer and Carer voice on the

implementation of strategies identified by consumers, carers, service providers and policy makers in the reform of mental health services. It will provide a statement on the commitments outlined in the First National Mental Health Plan (1992–1997) and the Second National Mental Health Plan (1998–2003).

From Consumer to Citizen: General Issues

- "Fringe" services metro /regional not service
- Aged care and young people/PEIRS not well covered in any area
- Charter for Mental Health — 4/5 not aware of it
- Transporting patients to out of area in paddy wagons
- Employment
- Training for employment/vocational
- Crossborder issues
- Transferring of patients to other area, or internally in the area which is tyranny of distance
- Rarely public transport to these service/hospital
- AHS don't work together, need to develop relationships and work together to benefit consumers/carers
- Charter of Victims Rights (Victims Rights Act 1996)
- Resistance from General Hospitals to service consumers
- 2 areas with a 24 hour service
- Budget takes priority over needs and often limits managers to expend monies on consumer areas
- GP's partnerships exist, but not yet expanded enough across the networks
- Standards
- No paid advocates
- Consumer position: 1 position, only in central part of the
- Carer position 1 (NEAHS)
- Guidelines for payments—no for all rural areas
- Psych. 1 only. 2 visiting (NEAHS)
- Government responsibilities. Not aware of budget/where the money goes (NEAHS)
- Policy
- No respite (major issue)
- Issue 10-1xdval dx issues-10ATSI positions in AHS
- Run public forums in networks
- Patra of Griffith is Patron of CAG
- Training is being negotiated with AHS and they are providing training in consumer identified areas
- Working and putting in submissions for consumer positions but not successful to date
- Yet to be achieved independent assessment services
- High vacancy rate for staff impacts on ability of consumer to receive services
- Money not moving into community services
- Working in partnership with health practitioner to assist consumers
- Commencing work in partnership
- No paid advocacy, but reimbursement for expenses

- Partnerships, NGOs, accommodation
- No respite
- Consumers work as rehabilitation assistance
- Vocational programs in partnership
- No paid consumer position
- No identified consumer forum

Rural/Country

1. What is happening in your area?
2. What would you like to see in the future?

- More resources
- Paid CAG positions
- Paid advocates
- 1 permanent 4
- Better respite
- Better rehabilitation. services
- Enable C &C to work independently, and also with other service
- Paid and independent advocates
- Resource centre–interagency
- Suicide prevention
- Mobile outreach
- 1800 in all areas
- Honesty
- Accessible and user friendly services
- Appropriate transport options for consumer being transported to services
- Support group for C&C
- "Comment that its still tokenistic"
- Multidisciplinary workers
- Division of GP-not consumer friendly
- Consumer worker
- Paid reps. consumer advocates
- No independents assessment
- 1 respite
- No independent assessment
- No training C&C
- No consumer positions/network
- No guidelines for payments
- Paid 2 people to attend conference
- Partnerships
- 4 a month
- Not aware of funding or where it comes from

- Paid Advocacy
- Supported accommodation

Metropolitan

What is happening in your area?

- Consumer network on the way of meeting the National Standards for Mental Health Services (National Standards 3)
- Only a small group of young people with D.D. being targeted-activities being run but only few attending
- NS Consumers being sponsored to go to NSW CAG and also education and training
- Some of the NSMHS being met but not all
- Some promotion of community acceptance
- Process for NGO's have of be accredited and must incorporate consumer participation and tired to funding for Health NGOs
- Workshops to see how the standards being met: Northern Sydney
- Nurses have placed a ban on doing anything re accreditation and quality assurance processes
- NSW Assoc for M/H re promotion m/h week
- NSH-Consumer and Carers Alliance providing training to staff
- Participating with Lemon Looning game for staff
- Training by consumers and carers to NSH Graduate Medical Students
- B Miles have consumer advocates involved in their service
- Consumer employees in all areas
- Area coordinator's position of S.E. Sydney currently vacant

What would you like to see in the future?

- NGO and neighbourhood centres be targeted
- Need consumer consultant programme specifically designed e.g.. educational package standards
- More education to staff in consumer issues including reception staff
- NSW CAG to take up the issues of the ban by nurses having a ban on accreditation and quality assurance processes
- Look at training e.g. NSH Consumers and Carers Alliance Training manual for staff and consumer and carer participation
- Need more training in networks, letter writing, reports, policy writing and complaints procedures Local Community Services Association (LCSA) guide re reason why to write policies
- NSW Association for Mental Health put projects on the web site and be regularly updated
- Access to and awareness of mental health services including NGOs as well as consumer groups
- Crisis Teams to directories of mental health services
- Need service providers referring consumers to consumer groups
- More education of service providers re consumer and carer groups
- Have consumer offices near or in rehabilitation. services and centres
- A consumer policy officer in each Area
- Consumer advocates/consultants may be there but not widely known

- Strategies for handling and reducing stigma: both individual and groups
- Lobby for bulk billing
- C & C pamphlets in Centres for M/H
- More young people as consumer advocates and education available
- Directory of psychiatrists who bulk bill
- Psychiatrists and service providers who are gay and lesbian friendly
- Ministers of religion being trained in mental health
- Increase in funding for NGOs and community organisations
- Support for staff who have a mental disorder

Other metropolitan areas

What is happening in your area?

- Good consumer advocate position
- Newsletter is effective
- Stonewalling
- WS consumers organised, effective
- Municipal Council run groups very effective
- 2 weekly standards evaluation meeting
- Carer network
- Carer position
- Paid advocacy
- Bilingual counsellors
- NESB advocates
- Given new meds but not enough support given in CHS
- Carer network

What is not happening?

- Standards not being implemented

What would you like to see in the future?

- Training
- Financial support
- Consumer positions needed
- Support for working carers
- No carer support worker
- Rights only in English. More translation of documents
- Gender specific respite for carers and consumers
- More support for vocational projects
- No security of employment for consumer workers
- Need an award for consumer workers
- Need insurance (?) for workers

unsolicited comments from the delegates during the conference

- Important for professionals to see us as we are: ordinary people, and ordinary people with great qualities

- Also, how about some gratitude to professionals for their help and tolerance

- Respite

  - More of them

  - Gender specific

  - Consumer and carer respite required

- Step Down Facilities

  - For people being discharged from hospital but not ready to go home

  - Less restrictive than acute units

  - Time limited with specific goals to be developed encouraged, reviewed and congratulated

- Training

  - Consumers "partners" in all training—staff, GPs, police, ambulance, students (undergraduate or placements), courts/magistrates

- Employment

  - Consumer Workers Award to cover hours of employment/rates of pay, job descriptions, award type and level.

- Democracy

- Participation

- Transparency

- Accountability

- If there is another consumer conference how about consultation from consumers?

- How is it fair? I got sick and DOCs took them off me and I don't know how to explain why

- Strategies are needed to cope with and reduce stigma (both as individuals and groups)

- Education is needed for ministers of religion who often deal with mentally ill people

- What about having next Conference in the country?

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