A Submission

Committee Secretary
Senate Select Committee on Mental Health
Department of the Senate
Parliament House
Canberra ACT 2600
Australia

Phone: (02) 6277 3034
Freecall: 1800 465 004
Fax: (02) 6277 3130

Merinda Epstein (Ms)

- Victorian Sate Representative on the National Mental Health Consumer[1] Network (ANMHCN)
- Member representing mental health on the Consumer Advisory Committee of the Australian Council for Safety and Quality in Health Care (ACSQHC)
- 2004 winner of the Australian Human Rights Award (HREOC) for 15 years contribution to the lives of people living with mental illness in Australia
- 1994 – 1998 Independent Consumer member of the National Community Advisory Group on mental health (NCAG).
- Policy Officer for the Victorian Mental Health Legal Centre;
- Member of the Victorian Mental Illness Awareness Council (VMIAC); and
- Consumer representative on the Australian Health Ministers Advisory Committee for the evaluation of the First National mental Health Strategy.

---

[1] The word ‘consumer’ is the word chosen by people with mental illness in Australia. It is not a great word and many people with mental illness feel uncomfortable about using it especially as it places us within a context of economic determinism. However, we do use it out of respect for an autonomous consumer movement in this country. Overseas there are many alternative words used. In Britain and New Zealand the terms ‘User’ or ‘Service User’ are used; in the USA ‘Survivor’ is used and on the internet it is often abbreviated to C/X/S (Consumer, ex-Patient Survivor). For a useful discussion about the terms ‘consumer’ and why we use it see discussion by consumer thinker and writer, Allan Pinches - http://www.alphalink.com.au/%7Ealpin/con_name.htm

Forward

I would like to thank the Senators from all parties who have helped to make this Inquiry a reality. People like me who have been living with mental illness for most of our adult lives have fought very hard to get our voices heard. This has been very difficult to achieve partially because of the high level of discrimination both in the community **and** in health[2] and mental health services themselves[3].

---

[2] This morning I was talking to a consumer who was telling me that recently she went into a large public hospital to have an orthopaedic operation and the first thing a staff member said to her was, "Oh! I see you've got a personality disorder! Are you going to behave yourself?" This person, <u>a fifty year old woman</u>, was really upset and angry. She said it felt just like she'd been told, "Oh! I see you have a criminal record." She asked me, "what possible relevance could this bit of information have for the surgery she was admitted for."

[3] Epstein M. and Olsen A. Mental Illness: Responses from the Community in *Mental Health in Australia-Collaborative Community Practice* Meadows G. and Singh B. eds, Oxford University Press 2001 p 17

Part One: Consumer Participation

The First Strategy in the early 1990s was courageous. It was an imperative document for consumers because for the first time in the history of mental health delivery in Australia formal recognition was given to the United Nations Statement of Human Rights. It was also an essential document because it paid central attention to new roles for consumers. No longer could we just be seen as patients (sick people). Now there were roles for us as representatives of consumer opinion, advocates, educators of the mental health workforce, speakers, visionaries and so on.

Unfortunately this radical conceptual impetus has slowed down to a crawl during the life of subsequent strategies because:

1. of a significant lack of funding to properly support rhetorical promises to consumers;
2. the latter strategies were strongly influenced by groups, including professional groups, who felt ‘left out’ of the first strategy and were clawing back political territory;
3. consumer participation became more corporate and more controlled;
4. of the demise of the National Community Advisory Group on Mental Health (NCAG);
5. of an inability of the Mental Health Council of Australia (MHCA) to take over where NCAG left off; and
6. of the starving of funding to the peak consumer organisation in Australia (National Mental Health Consumer Network);

Recommendations

At the level of National policy funding urgently needs to be found to:

1. Reverse the trend towards starving the democratically elected peak consumer voice – the National Mental Health Consumer Network - of funds. In my opinion it is presently funded to fail and many politically astute consumers are questioning whether we would be better off to pull out of these arrangements entirely and become an oppositional force rather than a pretend partner.[4]

2. Fund a centre for consumer perspective studies and a curriculum that can be taught by consumers to **all** mental health professionals[5] This would also contain a consumer research capability and clearing house for consumer perspective written material.

3. Research and develop guidelines for advising State and Territory governments as well as local services, private services and Non-government organisations employing consumers in a variety of roles and at a variety of levels of seniority. This must be done in partnership with consumer organisations and consumers with experience of working in the mental health system. This would include an award structure and guidelines for promotion and conditions for employment which build in the special needs of people with psychiatric disabilities.

---

[4] As it stands at the moment the network has one worker to service consumers right around this country. Several members of the Board of the Network have no phone and no email so half the budget goes into basic communication needs that other professional groups would not even have to waste time thinking about. There is almost no capacity to consult with the consumer constituency. It is an absolutely unsatisfactory situation.

[5] This was a key recommendation from a National Mental Health Strategy funded project looking at the education and training needs of the mental health workforce. This project (Deakin Human Services) was in my opinion the best example of consumer participation and consultation that has come out of National Mental Health Strategy funding. All consumers who were involved and many of the professionals as well were (and are) very enthusiastic about both the process of consultation and the recommendations. (Learning Together – Education and Training partnerships in Mental health National Mental Health Strategy 1999)

Part Two: Definitions of legitimacy and priority

During the First National Mental Health Strategy the words serious mental illness were used to describe public service priority however this term was not defined. This was a significant weakness of the first strategy. In this submission I draw attention to some of the practical implications of this lack of clarity not only during the life of the First National Mental Health Strategy but also in residue effects filtering into State and local practice subsequently. The imperative is that although issues of priority will always be fraught and fought for, since the emergence of the First National Mental Health Strategy some groups (and I have referred specifically to people labelled as having Borderline Personality Disorder and people too often not recognised as having Dissociative Identity Disorder) have been so badly marginalised that it will take a reversal of policy and a radical retraining and reorientation of clinicians to overcome the systemic neglect at the State policy and local level. It is also important that consumer perspective in relation to who gets what, why and where needs to be listened to very carefully when policies are being drafted in the future.

Recommendations:

1. Priority language must be re-thought and priority groups defined with as much attention being paid to ‘internal life chaos’ and ‘pain’ as ‘danger to the community’ and ‘diagnosis’. Definitions need to be clear, and supported by a transparent logic.

2. Language of priority must avoid prioritising men’s presentation of distress over women’s presentation of distress. For example, violence should not be rewarded with service priority.

3. Consumers must be reassured that there are not ‘good’ and ‘bad’ ways of being mentally distressed. Day to day assumptions by staff that some things are ‘genuine’ and some things are not must be publicly challenged at the level of practice and rhetorically challenged at the level of policy formation.

4. Consumers with experience of childhood abuse and trauma must once again be listened to and treated with respect and as a priority regardless of diagnosis.

5. Derogatory labels such as Borderline Personality Disorder must be examined and new, more respectful, and more accurate terms such as Complex Post Traumatic Stress Disorder be considered. Consumers must decide how they would like their distress to be described.

6. Each State must be encouraged to develop State-wide ‘Borderline Personality Disorder’ services that are responsible for training staff, supporting consumers, and providing tertiary care. These services must employ consumers with experience of ‘Borderline Personality Disorder’.

7. People with experiences that some clinicians call Dissociative Identity Disorder (DID) must be eligible for ongoing psychotherapeutic services in the State system regardless of what language is used to describe their distress.

Introduction

1. In this submission I have chosen to speak only to the first Term of Reference :
    a. *the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress***.**

   I have done so by reflecting, **from a consumer perspective**[6], on National policy determination post the publication of the 'Burdekin Report'[7] and the initial enunciation of the First National Mental Health Strategy in the early 1990s. I will also speak **from a consumer perspective** about the interpretation of the First and subsequent National Mental Health Strategies and the 'pick up' of the language and direction of these Strategies by State mental health authorities.

2. What is written here does not just represent my views. I am very involved in several health consumer organisations both mental health and physical health and both at a State level and at a National level and have consistently been involved since 1990. These organisations are listed above. The positions put forward here come from a recognised **consumer body of knowledge** which is significantly different from and as important as a professional body of knowledge or a sector body of knowledge.

3. I would very much like an opportunity to follow up what I've written here face to face with Senators because I am now perhaps one of the most experienced consumer players from the 1990s who is still heavily involved in National and State mental health politics and policy development.

4. I have chosen not to put my views re- Terms of Reference (b) through to (l) because I have already made a contribution to submissions submitted by:
    a. The National Mental Health Consumer Network;
    b. The Victorian Mental Health Legal Centre; and
    c. Insane Victoria

I have, however, drafted responses to each of the other references and would be happy to speak to them in an interview.

5. In the interests of clarity and brevity I have chosen to write about what I think are the **two most important initiatives of the First National Mental Health Strategy:**

---

[6] 'Consumer perspective' is now being recognised as a health discipline in its own right. It is essential that this is understood. Seeing policy through the viewfinder of personal experience is essentially different from seeing it through the eyes of a 'carer', 'a clinician' or 'policy maker' for example. Up until the time that the validity and intrinsic value of consumer perspective is truly understood and routinely resourced, respected and actively sort the mental health system will continue to operate with a black bandage over one eye.

[7] Human Rights & Mental Illness – the Report of the National Inquiry into the Human Rights of People with Mental Illness - 1993

- Consumer participation in mental health decision making; and
- Serious Mental Illness (SMI) and the problems of defining priority

6. I will also send[8] an annotated copy of a collection of my cartoons which reflect on common practice in mental health systems and services over the fifteen years that I have been actively involved**..**[9] It is important to understand that 'consumer language codes' are different from bureaucrat speak and/or the jargon of much clinical language. Please don't dismiss the cartoons as peripheral because they are the best articulation of consumer language that we presently have access to.

7. Consulting with consumers is sometimes very difficult. The consumer movement now has experience. I have provided some dot points at the end of this submission about how we have found it can be done in a way that privileges consumers speaking for themselves instead of relying on commentators who have chosen to represent our circumstances often without permission to do so.

---

[8] I will send by mail as it is too big a file to send as email.

[9] Consumers throughout Australia have used these cartoons to help express our lived experience of mental illness, mental health services, our very special sense of humour which continues to surprise and sometimes confront 'non-nutcases' [grin]; our often unorthodox ways of fighting discrimination; our affiliations with other social causes, our development as an important social movement and our take on attempts at consumer participation in mental health service planning and delivery. Some of these cartoons have appeared in material published under the First and subsequent National Mental Health Strategies. Others have been published in the consumer literature and by the Human Rights Commission of New Zealand.

DISCUSSION

Term of Reference

a. the extent to which the National Mental Health Strategy, the resources committed to it and the division of responsibility for policy and funding between all levels of government have achieved its aims and objectives, and the barriers to progress;

PART ONE

Consumer participation in mental health decision making

More than just ‘patients’

The Report of the National Inquiry into the Human Rights of People with Mental Illness (Burdekin Report) and the First National Mental Health Strategy which appeared at the same time (1992 – 93) were significant documents for consumers. The Burdekin Report was not only a tangible reflection of the things consumers knew were happening to them in society and in services it also put forward strong recommendations for change including changes to the role that consumers of the future would play in all aspects of service delivery and deliberation. **For the first time in the history of mental health policy in this country we were perceived outside the sick role.** This was a very significant change in policy direction and one of the key platforms of the First National Mental Health Strategy. There was a new vision for consumers to start playing vital roles in ‘the system’; as peer supporters, educators of the mental health workforce, as consultants to the system, advocates and other paid roles in service delivery; consumer evaluators and decision makers; service auditors; researchers; orators and visionaries.

National Community Advisory Group on Mental Health (NCAG)

Perhaps the most important aspect of the First National Mental Health Strategy from a consumer perspective was the appointment of an influential committee of consumers and carers that was to become known as the National Community Advisory Group in mental health or NCAG. The appointment of NCAG was significant for many reasons but its greatest contribution was perhaps emblematic in that it was official recognition that the lived experience of people with mental illness and carers was significantly important and should be a respected resource driving change in the planning, operation and evaluation of all aspects of mental health care. NCAG reported straight to the Minister of Health.

However NCAG members met resistance from a system that was threatened by the power it was bestowed under the First Plan. Many mental health professionals had never before been asked to sit on committees where they had no more power (on paper anyway) than the person sitting next to them who might happen to be a consumer member of NCAG. Trisha Goddard[10] chaired this committee. Her appointment immediately challenged public stereotypes of what it meant to be mentally ill. During the years of the First Strategy, consumers and carers slowly moved in on all decision-making fronts. This was

---

[10] a well known and easily identifiable television personality who has now moved back to Britain

truly significant. I sat on NCAG as a consumer representative during those years in the early to mid 1990s and experienced first hand the resistance and reluctance of some powerful medical groups to take us seriously and then this slowly changing as there was a realisation that NCAG was not an aberrant detour from the main agenda but was rather here to stay and something that mental health decision makers must learn to work with. During the life of the First National Mental Health Strategy significant funds were being channelled into initiatives to involve consumers and carers at the National level. This was not followed in States and Territories. Victoria was the only State that had a peak consumer organisation. This was a product of a much longer and more engaged commitment to the Non-government sector in this State.

Sitting on NCAG and being asked to bring consumer knowledge to a broad spectrum of projects funded by the First National Mental Health Strategy was difficult. This was partly due to defensive institutions very quickly adapting to maintain their authority. It quickly became apparent that often we were sitting on committees where we did not have the numbers and despite much effort and input on our part our positions were tokenistic and we were making very little difference to the decisions being made. Secondly, NCAG was not democratically elected. Our positions were Ministerial appointments. This bred some disquiet at the grass roots level from consumers. People living on pensions and disempowered in nearly all aspects of their lives often saw us as a privileged class of consumer and they resented it. I understand this disquiet. It was made worse by the lack of resources to enable us to consult adequately. **Nontheless starting from a history of absolutely no consumer involvement I think the promotion of 14 consumers and carers (representing each State and Territory) to positions of prominence and authority was one of the most important achievements of the First National Mental Health Strategy.**

State Community Advisory Groups

Significantly the Commonwealth tagged consumer and carer participation as part of the State funding agreement under the First National Mental Health Strategy. All States and Territories were required to fund State Community Advisory Groups. These met with mixed success and were all abandoned by the year 2000. My opinion is that many of them were not entered into with determination and sufficient resources to enable them to work. I don’t think it was failure of the idea as much as it was failure of resourcing. It was also a product of State/Commonwealth political relationships. Measures dictated to States through Commonwealth/State funding agreements were often resisted at the State level.

Second and Third National Mental Health Strategies

The promise of NCAG was never fulfilled. Neither were the hopes of consumers that the National Mental Health Strategy would bring about significant and lasting change to the mental health system. The tragedy and thing that makes consumers very angry and disenchanted is that the promises of the First National Mental Health Strategy have been skittled through a lack of commitment to properly funding ongoing consumer objectives despite the fact that these have been repeatedly and carefully articulated. Where the First National Mental Health Strategy was courageous and revolutionary particularly in its bold endorsement of consumer and carer capacity to drive urgent change, subsequent policy has been reactive to the agendas of powerful professional lobby groups and individuals. Interestingly the carer voice has been able to keep astride these changes as politically experienced and confident carers have taken on positions of influence at the National level.[11] The consumer voice was unable to keep pace with this rise in the authority of carers. Consumer organisations are now seriously under funded in relation to equivalent carer organisations right around the country.[12]

The Mental Health Council of Australia and the concept of 'critical mass[13]'

The Second and Third National Mental Health Strategies have seen the diminution of the collective consumer voice. NCAG was abandoned in the late 1990s and I was in the room when Minister Wooldridge promised us that we would be replaced by a new National Council that would continue to competently represent us. This council became known as the Mental Health Council of Australia (MHCA). I sat for a few months on the provisional Board. Having responsibility for drafting a constitution we tried to build in clauses that would ensure that the consumer voice did not get swamped by all the professional and other voices which we knew would now demand to be part of this new and potentially influential body.

It was obvious right from the beginning however that the MHCA could not be for the consumer voice the strong articulation that NCAG had been. Put simply, we would never have the numbers. Having a critical mass is essential for any process that attempts to include consumers as equal players. Having the numbers is essential because we don't have power derived from professional authority. Demanding critical mass has become a salient aspect of consumer politics and the politics of all relatively disempowered groups in society. Unfortunately we often do not have the numbers to demand more consumer perspective input or, at least, the balancing of the consumer voice with the professional one. The reason that NCAG was so successful was that it privileged the consumer and carer voice. This was integral but could not be repeated by this new body. Put simply, there are only four national consumer organisations that could even potentially become voting members of the Council. No matter how loud these groups might try to be their voice will always be diluted as each new professional organisation joins the Board of the MHCA. We (NCAG members) warned the government that this would happen but the Government at the time was clear about its wish to hear from one key organisation at the Commonwealth level and not from disparate bodies. The two existing national representative bodies were defunded.

---

[11] First John McGrath and then Keith Williams both ex-politicians who have filled influential roles and as Chair of the Mental Health Council of Australia

[12] In a recent forum in Melbourne one of the important issues that was raised was that carer organisations tend only to represent a small cross-section of 'diagnoses' (ie. mainly psychosis) and consumer organisations are much more broadly based. Later in this paper I will write about consumers who are diagnosed as having Borderline Personality Disorder (BPD) a notorious sentence indeed. This is a group that is under-represented in carer political lobbying initiatives.

[13] The size or amount of something that is required before something can take place – Encarta Dictionary (U.K)

The corporatisation of the consumer voice and the loss of history

It did not take long after the demise of NCAG and the emergence of the MHCA for the history to get blurred and then forgotten. This has been a major problem for consumers because we have desperately inadequate resources to enable new consumers to understand the history of consumer participation in this country (and internationally) and learn from the lessons of over a decade of consumer participation in National policy here. This lack of history has been a retardant to the growth of the capacity of the consumer voice to engage with the debates and influence policy in an ongoing way. At a more sinister level it makes us vulnerable to organisations that are trying to keep control of the political agenda as they just react to challenges by finding new consumers who for the present time at least do their bidding. Many of these consumers do not represent a constituency. Questionably motivated organisations and some Government bodies continually choose to engage with those who won't (or don't yet have the confidence to) challenge the status quo.

There is a very tricky balancing process going on as 'cooperative' consumers rise to the top and are selected usually by **well resourced non-consumer** organisations to 'represent' the consumer voice. At the same time there has arisen a new language of legitimacy. Several influential professional lobby groups and agencies have found it useful to de-legitimise some of the more forceful consumer groups and individuals with claims that they do not represent 'the really sick ones'. Unfortunately carer lobby groups have sometimes colluded with this sentiment which divides and alienates the community voice and which refuels professional group criticism that consumers and carers are so busy fighting each other that they've lost the plot in relation to service reform. I find this argument unconvincing. It is imperative that both groups (consumers and carers) get heard as **separate** voices **both** of which are important to hear if substantial change is going to happen for people living with mental illness in this country.

Consumer Participation in 2005

The suspect and reactive processes that drove both the development of the second and third strategies and the funding arrangements have led to the position that we have today. This is typified by:

1. National and State and Territory governments using the rhetoric of consumer participation without funding it anywhere near adequately and without embracing it with enough energy to support ongoing consumer articulated change in service culture and practice.

2. Many local services also using the rhetoric of consumer participation without actually doing it.

This is essentially dishonest. In order to 'do it' the funding needs to increase tenfold. Even then it would still only be a small impost into Sate, Federal and service level mental health budgets. There are examples at a local level of services proudly announcing they have budget neutral consumer participation policies and practices. This is impossible. There is now significant evidence that you get what you're prepared to pay for in relation to consumer perspective input in all the different areas of expertise consumers are now providing (eg. Consumer Educators, consumer service auditors, consumer peer counsellors etc.).

It is a unsatisfactory that twelve years after the publication of the Burdekin Report and the First National Mental Health Strategy we still have:

1. no consumer run mental health services[14]. We haven't even put resources into exploring successful consumer-run services overseas;
2. no State and Territory (other than Victoria) has a peak consumer organisation;
3. very few consumer run enterprises[15];
4. still tokenistic consumer participation;
5. some States and Territories with no or few consumers employed by services;
6. still some States and Territories with no funding going into consumer participation at all.
7. some policies that still mix up the consumer voice with the carer voice despite the fact that the differences between these two different voices can be profound;
8. Still a high degree of professional suspicion about the motives of consumers who are passionate about consumer participation;
9. Legal advocacy through a designated Mental Health Legal Service available to consumers only in a very limited way and only in Western Australia and Victoria;
10. Only one specifically defined Consumer Academic throughout all courses which train mental health professionals around Australia.

Part One: Conclusion

The First National Mental Health Strategy offered us hope for so much more than this. The Burdekin Report was clear that one of Australia's pivotal needs in mental health was for services and systems to learn from the 'lived experience' of consumer and carers. **We are not just one of many stakeholders.** We are what Wadsworth defines as the Critical Reference Group[16]. Services are designed to provide mental health services for us. Put crudely, arguments about stakeholders having a necessarily shared stake , equal political power, and equal interest only in the wellbeing of the consumers they serve is obviously nonsense. My life and death, connected intimately with my mental illness, is of much greater importance to me than it is to my psychiatrist or my case manager. We do not (on paper) have mental health services in order to find jobs for aspiring clinicians and researchers, or so people can become famous or earn a living. As nice as these things might be they are secondary. The First National Mental Health Strategy recognised us as the Critical Reference Group and this upset some individuals and organisations who were used to wielding power in the sector. The first strategy put human rights prominently to the foreground. It documented our right to be treated with dignity and at all times in

---

[14] There is ample evidence from overseas that these work (Netherlands particularly)

[15] There are many examples of successful consumer-run, profit generating enterprises in Europe and the USA. There is token acknowledgement that empowerment of consumers is vital for recovery but no investment into the structures and skilling that consumer-run enterprises have been shown to bring overseas.

[16] Wadsworth, Y. *Do It Yourself Social Research,* Allen and Unwin, Sydney 1999 p. 11

accordance with the United Nations Charter of Human Rights. The First National Mental Health Strategy gave consumers and carers an unassailable role in the 'new' order with responsibility to supervise the transition towards better and more accountable services. Unfortunately during the years following this strategy, progress towards these goals has slowed to a walk and consumers are frustrated and angry.

PART TWO

Serious Mental Illness and the problems of defining priority

From serious mental illness to SMI – the problem of definition

In the First National Mental Health Strategy the term serious mental illness was used. It was not defined in the documents. Not being defined it was open to lobby groups and influential professionals dictating their own definitions. During the life of the first strategy the term moved from serious mental illness to Serious Mental Illness to just the reductive shorthand - SMI. Groups such as SANE took licence with the term and promoted the idea that it was a description of psychotic illness. This was not in fact true nor was it the intention of those who drafted the first strategy. I sat as the consumer representative on the committee put together by the Australian Health Ministers Advisory Council (AHMAC) to review the achievements of the First National Mental Health Strategy. We spent a considerable amount of time discussing the use and misuse of such a loosely defined term[17]. I put forward the position that some consumers were very angry. Regardless of the degree of their distress and 'disability' they were being refused services in public mental health facilities simply because they had failed to attract the right diagnosis. I was aware of many cases where people's mental distress was demonstrably serious but they were turned away because their distress did not match the criteria for psychotic illness[18]. This divided consumers and it divided the mental health community. We all started to fight each other for legitimacy because the resources were stretched.

---

[17]

"*The term 'serious mental illness' represents the simplification of…complex ideas. Once it appeared in the mental health lexicon, its use spread rapidly and was subject to variable interpretation."*
In Australian Health Ministers Advisory Council by the National Mental Health Strategy Evaluation Steering Committee, Evaluation of the National Mental Health Strategy Final Report; December 1997

[18] "*personality disorders, including BPD,… clearly meet the accepted (*The International Statistical Classification of Diseases and Related Health Problems, tenth revision (ICD) *and* Diagnostic and Statistical Manual of Mental Disorders *(DSM) criteria for 'mental disorders' and involve a level of distress and dysfunction comparable to Axis 1 conditions.* Guidelines For The Treatment Of Borderline Personality Disorder In The New Zealand District Health Board Environment (unpublished) Mental Health Commission of New Zealand, 2004 p.6

National Mental Health Strategy and its effect at a local service level on triage and treatment

As a consequence of a public outcry from consumers, some carers and some clinicians and recommendations from our report to AHMAC the term Serious Mental Illness was dropped from the second and subsequent policies and plans. Terms such as ‘Major Mental Illness’ and ‘Severe Mental Illness’ were subsequently tried. This has done little to influence criteria for service at a State and local level.

I have written on many occasions about the role of Crisis Assessment Treatment (CAT) teams and triage criteria that tend **to only take psychotic illness seriously**. Consumers know this. Over years since the language of the First Strategy had disappeared from national documents many consumers were still experiencing a system of triage which directly related back to the badly thought through language around SMI in the first strategy. For example, we know that if you have Borderline Personality Disorder (BPD)somewhere in your history you’ve probably got a very limited chance of attracting a service regardless of the seriousness of your pain or functioning. Alternatively, if you’ve managed to attract a diagnosis of Schizophrenia your chances improve markedly. We know that regardless of your diagnosis if you tell the CAT team that you are suicidal this very rarely attracts a service any more. If it does it will only be if you have recorded that you have a psychotic illness. It is much better to tell them that you are worried about urges to hurt or kill someone else (homicidal). Of course, there are significant gender implications here[19]. If you are feeling suicidal you know that the first questions you will be asked will be, “do you have a plan?” And “do you have the means?” Knowing this you can be prepared so that you don’t just get patronised and ignored. If you have sufficient insight to know that you should be in hospital this is probably sufficient information for the gatekeepers to say you have ‘insight’ so you are not a priority. This also has gender implications. None of these strategies has anything to do with “attention seeking”, “manipulation” or any of the other horrible labels that are readily attractable. They are about consumers helping each other to understand an otherwise daunting system.

National Mental Health Strategies and consumers perception of the role of the private sector

Since the problem of language was identified, there has been an effort in the second and subsequent national policies to broaden the scope of public mental health services. There are many conceptual problems here. An enormous amount of Commonwealth Government money is filtered off to private psychiatrists some of whom practice almost unaware and unconcerned about the priorities of the National Mental Health Strategies. Since the end of the first strategy and the recognition of this as a priority attempts have been made at a National level to more actively include psychiatrists through dialogue with the Royal Australian and New Zealand College of Psychiatry (RANZCP). Nonetheless, psychiatrists practising privately with a medicare number cannot be told what to do and who to see.

---

[19] The Manager of an outer Melbourne Area Mental Health Service admitted to me recently that the service is so pushed by having to treat young aggressive men with drug induced psychosis that they barely have time to register the needs of anyone else.

Their remains a profound misdistribution of psychiatrists with few practicing in poorer suburbs and rural areas and none in remote locations. The National Mental Health Strategies have tried to conceptualise innovative ways that such problems can be addressed. However, the problem persists. This in itself primes the discontent between the Commonwealth and States because the medicare responsibility is a Commonwealth one and public mental health provision is the responsibility of the States and Territories.

What has diagnosis got to do with a capacity to pay?

Dr Alan Rosen, a public sector psychiatrist in Sydney who is well regarded by many consumers, jokingly coined the term, “met un-need’, to describe what he saw as a lack of accountability by some private sector psychiatrists. Justifying public service emphasis on psychotic illness some argue that other forms of mental illness (eg. range of depressive illness, anxieties and phobias for example) get seen in the private system and by private practitioners. From a consumer perspective there are many problems with this argument. **It mixes up issues of poverty with issues of diagnosis.** It is perhaps reasonable to argue that many people with chronic psychotic illness might be on pensions but not all by any means. Nor is everybody with depression (for example) wealthy enough to go to private hospitals and pay private psychiatrists.

The untested assumption that wealth correlates with diagnosis needs to be challenged. The degree of disability and the degree of suffering does not only depend on diagnosis either. National lobby groups such as SANE have a great deal to answer for here. Consumers in Victoria have somewhat crossly asserted that ‘SANE”, the acronym, stands for **S**chizophrenia **A**nd **N**othing **E**lse!

However, there were also contradictory messages filtering down to the consumer community. The significant funding and very high profile of beyondblue have further amplified this issue of legitimacy. Many consumers and carers witnessed ‘money being thrown around’ by an organisation, which represents one group of consumers only. People saw Jeff Kennett more and more often and resented the fact that people with depression ‘seemed to be getting everything’. Some consumers and carers got the impression that people with depression were somehow now the ‘chosen people’.

However, political generalisations about this are as personally and publicly damaging as political generalisations that serious equals psychotic. People experiencing depression are not the ‘chosen people’. My sister killed herself after thirteen years of hell living (well half-living) with serious unipolar depression. Whilst she was alive she was hospitalised many, many times (in the private system). She’s had over two hundred ECT treatments. She had tried to kill herself many times before. Quite frankly, I find it infuriating and very distressing that anyone should claim that depression is not serious by definition. My sister did not die from something that was not serious. The drive for policy renewal through vehicles like the National Mental Health Strategy needs to be tightly informed by the lived experience of consumers because when messages get entangled and meanings are crudely politicised people who find themselves on the wrong side of definitions of legitimacy can not only be refused services, they can also be psychologically damaged by the rhetoric.

A Special Case of Neglect: Borderline Personality Disorder and Dissociative Identity Disorder

The groups that I have a particular interest in are people who are diagnosed as having Borderline Personality Disorder (BPD) or Dissociative Identity Disorder (DID) – problems often labelled as ‘just behavioural’. **It fascinates and alarms me that what was happening to Cornelia Rau was deemed to be acceptable up until that point of time that her mental distress was labelled as psychotic illness.** Unfortunately, this is indicative of the lived reality for many other people whose experiences hover and cross over between something that is deemed to be psychotic and something that is deemed to be behavioural. On the Four Corners program about Cornelia Rau several professionals dismissed her plight completely because it was deemed ‘just behavioural’ regardless of her psychological pain and her inability to cope. **The community disbelief and anger came only when the system started to see her as someone with Schizophrenia.** Consumers recognise this judgement of ‘good’ versus ‘bad’ ‘mental illness’ as typical of the whole mental health system. **It is not just an abhorrent reality of Detention Centres.**[20]

‘Borderline Personality Disorder’ and Dissociative Identity Disorder[21]– simply missing from the National Mental Health Strategies

On learning that so many consumers with ‘just behavioural problems’ or with BPD or DID or other often undiagnosable syndromes very often have terrible histories of Complex Post Traumatic Stress Disorder[22] from childhood abuse you would think that policy makers would privilege their care as adults. However, the opposite is in fact true. There is simply no mention of this group in any of the National Mental Health Strategy documents even though the population prevalence of Borderline Personality Disorder (BPD) is about the same as the population prevalence of Schizophrenia.[23] They simply do

---

[20] Consumers were mystified by the lack of media attention on
(a) the fact that the inpatient setting in Sydney was so unbearable that Cornelia Rau found she had to run away from it in the first place;
(b) the fact that there seemed to be a Nation-wide sigh of relief when she was deposited in a High Dependency Unit at Glenside Hospital in Adelaide. Consumer critique of High Dependency Units (all over Australia) leads us to be very cynical about the ‘safety’ Cornelia was supposedly being delivered to. Our experience is that very often they are not safe places either psychologically or physically.

[21] I have used these horrible medical terms because this seems the only way that you can get people’s pain taken seriously but I do not like them.

[22] A diagnosis coined by the American psychiatrist, Judith Herrman

[23] Henry Jackson & Philip Burgess' 2000, *Personality Disorders in the community: a report from the Australian National Survey of Mental Health and Wellbeing and* [23] Philip Burgess, Jane Pirkis, Bill Buckingham, Jane Burns, Kathy Eagar and Gary Eckstein, Adult mental health needs and expenditure in Australia in *Social Psychiatry and Psychiatric Epidemiology*, Volume 39, Number 6; June 2004 pp 427 - 434

not exist in many National and State policy documents[24] and have, extraordinarily, even been left out of fundamental national prevalence research[25]. Ironically many consumers who have been diagnosed as having Borderline Personality Disorder and Dissociative Identity Disorder report that this steadfast refusal of national policy makers to recognise their existence mirrors the way they experienced abuse as children. They were, quite simply, invisible.

During the years of the First National Mental Health Strategy the interpretation of national strategy rhetoric by State mental health policy makers was absolutist in its denial that anything could be serious that was not psychotic illness. Directions were given to ‘get rid of’ ‘attention seekers’ and ‘manipulative women’ who would clog up the system further disadvantaging people with ‘real’ psychotic illness. People with DID and BPD labels were subjected not only to service refusal but also to ongoing systemic shaming as services manipulated the language of legitimacy to defend intake policies.

Discrimination ant a service level

BPD and DID (for example) were deemed to not be mental illness. Consumers with such labels claimed that they were discriminated against within services and they were. **It was not uncommon to hear clinicians referring to them derogatorily as ‘slashers’ many years after it would have been absolutely unacceptable for service providers to use the collective noun, ‘psychos’, to describe patients with psychotic illness.** During the evaluation of the First National Mental Health Strategy I tried hard to bring issues for people labelled in this way to the surface but time after time my pleas for inclusion were dismissed. It just seemed so blatantly discriminatory that I decided to speak and write about ‘Serious not-Mental-Illness’. That is, the needs of these people were so obviously serious and so genuine that dithering over definitions of illness was a waste of time and was the cause of enormous added damage and pain. However, over the last few years things have eased just slightly and only in some States. In Victoria there is now a grossly under funded but at least available Statewide Borderline Personality Disorder Service. There is almost nothing except expensive and intensive private psychologists with an interest in DID for people with Dissociative Identity Disorder.

---

[24] And when they are mentioned they are almost the group on the end of the list and with the lowest priority. I have also done some work which shows that the language that is used becomes discriminatory as soon as these two groups are objectified.

[25] There were two sizeable epidemiological projects funding under the National Mental Health Strategy in the late 1990s. One looked at what the sector called High Prevalence Disorders and the other looked at Low Prevalence Disorders. As admirable and substantial pieces of research these documents have become an extremely influential starting point for planning services and ongoing policy. However, when you look at the inclusion criteria for the Low Prevalence project you realise that Borderline Personality Disorder (BPD) and Dissociative Identity Disorder (DID) do not get a Guernsey at all. This is an artefact of the sampling method but the choice of sampling method is itself an artefact of quite blatant discrimination in the mental health community towards serious diagnoses, which respond to talking therapies rather than drug therapies. The impact of this is enormous. Whilst policy makers use the results of these epidemiological studies to justify ongoing policy decisions they are rarely candid about the total absence in the figures of certain groups of consumers. Both BPD and DID are low prevalence disorders and as serious as the low prevalence psychotic disorders but this is not in the data and is therefore not reflected in research, services, rhetoric or policy.

Following the First National Mental Health Strategy – psychotherapists have disappeared from public services

These issues to do with legitimacy, triage, policy directions and the distribution of insufficient resources also need to be seen in relation to the irony that is often very obvious to consumers but which seems to elude those in power. Many people who have been diagnosed as having 'syndromes' like BPD or DID which need long term psychotherapy or Dialectical Behavioural Therapy (DBT) and more intensive interpersonal relationships with therapists over a longer period of time (rather than medical drugs) are now 'out of policy fashion'[26]. Consumers recognise and are very concerned that since the publication of the First National Mental Health Strategy **public systems throughout Australia have lost a whole generation of psychotherapists.** We are angry about this and often frame our anger using language such as, 'needing to be treated like a whole person with a whole life' not 'a Borderline' or 'a Schizophrenic'[27]!

Part Two: Conclusion

The irony is that some consumers who have been literally ejected from the public system have found very special private psychiatrists[28] with an interest in BPD and DID and who use psychotherapeutic tools and 'talking therapies' either instead of or as an adjunct to drug therapy. Often, these clinicians are also refugees from the State system where they found their skills were no longer wanted. **In this sense it is for consumers with certain labels the private system[29] where they have found support and healing– with private clinicians providing the only appropriate service to special categories of very marginalised people**. It is an important point because it illustrates the contribution of consumer perspective. It is important to criticise a system of 'care' which unjustly privileges the already privileged, is geographically skewed, escalates fees and too often justifies this as part of the therapeutic process. However criticisms need to be muted by testing them **from the perspective of consumer experience**. From this perspective it is absolutely necessary that we do have a sustained critique of a system, or systems, which disadvantage the poorest and most marginalised but this needs to happen with careful

---

[26] This is justified by reference to 'evidence based practice' which **IS** in fashion. Consumers constantly confront this argument and our response is to say either, "what are you talking about. Look at me. I am the evidence" or to question where the money comes from to fund research. Where is the money to investigate whether consumer-run crisis services are less damaging than professionally run ones, or peer counselling is more effective than drugs once every two week and so on.

[27] Consumer throughout the world talk about using 'consumer first language'. This is a very important concept. Rather than defining us as a diagnosis (eg. A Schizophrenic or the mentally ill) the emphasis must always remain on the person (eg. A person living with Schizophrenia, or A person labelled as having Schizophrenia etc.)

[28] The territorial jousting between psychotherapists who happen to be psychiatrists and those who happen to be psychologists is not an issue that consumers particularly care about or want to get into except that our access to psychologists if we are on pensions is non-existent because they don't attract medicare numbers. We believe that the absence of psychotherapists from public services and the inability of most of us to pay for private psychologists puts increased pressure on psychiatrists using psychotherapeutic methods to be ethical and therefore to bulk bill or, at least, keep the out of pocket expenses minimal or, as some do, use a sliding scale of fees to maximally accommodate consumers with the least resources.

[29] BUT only a very small number of private psychotherapists etc. who are prepared to work in the western suburbs and also bulk bill. These people are held in very high esteem by consumers.

ears listening to consumer stories of the anomalies in practice. This is one of the essential values of consumer participation.

Consulting with Consumers.

Background:

The World Network of Users and Survivors of Psychiatry (WNUSP) which is the international peak organisation for people living with mental illness has the following slogan which we have now adopted in Australia as the motto for the National Mental Health Consumer Network (NMHCN):

"Nothing about Us. Without us."

An understanding about what this means right through the spectrum of involvement from grass roots consumers claiming their right to determine their own destiny to the maximum degree possible through to campaigners like me who are fighting at a systems level to bring about much needed change is central to this inquiry.

Below are some dot point tips that might help:

1. Consulting with consumers is difficult because everyone believes they can talk for us and on behalf of us. Carers do it, clinicians do it, Non-government organizations do it.
2. Sometimes this failure to let us speak for ourselves comes out of an illogical belief that because we (those with mental illness whom they hear speaking) can speak for ourselves we must not be the 'real' consumers who are, by self-defeating definition – too 'sick', 'too 'disabled' etc.
3. We also have problems being heard because we do not have sufficient National organizations and the ones we have can not 'take on extra staff to write submissions to the Inquiry'! . The wealthiest organized consumer lobby at the moment is 'blue voices" which is giving a voice to people who experience depression (which is great and they should definitely be part of the Inquiry) but they have some money from the beyondblue coffers to enable them to influence policy. Other organizations don't have this luxury. The only other groups at a National level are the National Mental Health Consumer Network (NMHCN) which has one paid staff member, GROW and an organization representing consumers who use private services which is supported financially by the Private Hospitals Association. (PHA).
4. As mentioned previously the NMHCN is funded to fail in that we have only a fraction of the resources available to professional lobby groups and lobby groups of professionals. It is imperative that the Senate Committee seek guidance from the NMHCN as this is (despite its limitations) the democratically elected voice of consumers in this country. Formally requesting our chair, Helen Connor, to address the Inquiry is imperative but it is also important to find out from the secretariat (Tyneal Hodges [secretariat@amhcn.com.au]) names and contact details for the State representatives who can organise ways for consumers to be available to give evidence to the inquiry in each State.

5. Only one State, Victoria, has a peak consumer organization – the Victorian Mental Illness Awareness Council (VMIAC). This fact tells you something in itself. This is an important organization (which preceded the First National Mental Health Strategy and is a direct result of consumers organizing themselves politically but also of a much richer history of NGO activity in this State). VMIAC needs to be directly included in the Inquiry for a number of reasons including the fact that this peak could perhaps be seen as a model for other States and Territories. But also, VMIAC has a good track record for organizing BBQ consultations with grassroots consumers both from metropolitan services and from rural services. Isabell Collins, the CEO of VMIAC, and Michael O'Brien, the rural and regional consumer advocate, could be asked to organize two BBQ consultations (attended by the Senators involved in the Inquiry); one for metropolitan consumers and one for regional consumers. There are a whole lot of rituals associated with these events and the sharing of food with people who otherwise rely on pensions is an essential part of providing an environment where people are not afraid to speak. The workers from VMIAC are experienced at running these in a way that enables lots of people to speak and prevents one or two people from hogging the floor. The essential ingredient however is that the decision to include grass roots consultations must be made early to give VMIAC time to organize.
6. Since the introduction of the First National Mental Health Strategy (post Burdekin) one thing that has changed is the roles that consumer play in the mental health sector. Prior to this strategy there was only one role for us and that was to be 'sick'. Now we have many different roles: consumer educators, consumer advocates, consumer consultants, consumer researchers, and consumer surveyors (National Mental Health Standards). These have all been significant changes (even if grossly under funded). However, in terms of the hearings it does mean that you should seek out **direct verbal input** from consumers engaged in each of these new roles. I think that this is an imperative step: My suggestions would be[30]:

Consumer Consultant: John Krochel from the Alfred Hospital in Melbourne;
Consumer Surveyor: Deborah Waddington from Perth
Consumer Educator: Cath Roper (Consumer Academic at the University of Melbourne Centre for Psychiatric Nursing Research and Practice) from Melbourne
Consumer CAG (Advisory Group): Douglas Holmes from Sydney
Consumer Researcher: David Webb from Melbourne
Consumer Advocate: Desley Casey from Sydney

It is inevitable that groups and people who are the professional equivalents of each of these people will demand to be heard by the Senate Committee. It is much less likely that consumers in the same positions will get an audience unless some positive discrimination is applied.

---

[30] I can help with contact details as needed

7. It will be useful to talk to Simon Champ (NSW), Leonie Manns (NSWs), Phil Iker (Townsville)or me to address the Senate Committee as we were the original consumers invited to join the first truly influential National consumer and carer Ministerial Advisory Committee (NCAG) in the early 1990s. NCAG was established as a direct response to the Burdekin Inquiry and as a direct result of putting into operation the requirements of the First National Mental Health Strategy. Those of us who were involved at the beginning are in a good position to comment on what happened then and what has happened since especially in relation to the issues which are of greatest importance to consumers.

8. My suggestion is that in each State forum you give as much time as you possibly can to comments from the floor. Others of us (including experienced consumers like myself or anybody put forward by the Mental Health Council of Australia) will be able to have our say in writing etc. We do not need to take up precious time at public meetings.

I hope this is useful. The NMHCN motto – “Nothing about us, without us**,”** is fundamental to everything. There is a long and sinister history of people who have been labeled mentally ill being locked away, silenced and ‘done to’ rather than ‘done with’. The culture that sustains this did not disappear with the closure of the big bins and we want it challenged. I was thinking that this was the single most important piece of advice I could give you when five minutes ago a friend and fellow consumer rang and told me that internationally consumers were suggesting that maybe we change it to; **“everything about us, with us”** because this is less combative and perhaps more constructive whilst still expressing the same fundamental sentiment. **A good rule of thumb is that about one quarter of the people who appear personally before the Inquiry should be consumers (this should not include carers) If this ratio does not seem to be happening then a red light should be flashing somewhere indicating that something has gone wrong.**

Merinda Epstein