Getting some action at a National level
– the lament of a tired campaigner

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Introduction

" I thought I would write my life story
but instead
I am just going to photocopy my arms"[1]

Very early in my days as an activist I was given a fantastic little purple book. It had been put together by young women from the Young Women's Group which was a group for young women with mental health problems who were homeless. It was very tiny. The young women had insisted on that because they wanted to be able to give it out to other homeless young women on the streets of Melbourne. Most of the contributions were from young women who had been at some time or other diagnosed as having Borderline Personality Disorder (BPD). I still have it and treasure it. It is very sad. The group was empowering and authentic. It also failed in all its efforts to get ongoing funding.

First Story

In 2001 I was working for the Mental Health Council of Australia and I was based in Canberra but I had a job that required me to travel widely through all the States running workshops on consumer and carer participation. When I was visiting Tamworth a consumer approached me. She had in her hand a copy of a document produced by the Commonwealth Mental Health and Special Projects Branch to educate the media about reporting on mental illness[2]. It was supposed to be a document that would enable and encourage accurate and compassionate, non-sensationalising reporting. This young woman complained to me about the representation of personality disorders in this document.

We sat down together to look at the document and these were the things that we found:

1. Each 'illness' (spectrum of 'illnesses') was presented one after the other but these were not in alphabetical order as would be expected. They started with

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[1] Young Women's Group, *In a Nut Shell*, no date

[2] Commonwealth Department of Health and Aged Care, Media Resource for the Reporting and Portrayal of Mental Illness , Commonwealth of Australia 1999

Schizophrenia, then Bi-polar, then major depression … all the way down to 'personality disorders' which were at the end of the document. There was a definite impression that this was in order of importance.

2. There were several pages about Schizophrenia and from there the emphasis was reduced and reduced until right at the end we had all the different personality disorders crammed into one paragraph with no attempt made to differentiate between them. Again there was a definite impression that the 'illnesses' at the front of the booklet were the most important ones.
3. The word 'suffering' had completely disappeared by the time we got to the label-'personality disorder'. The language was judgemental and presented the person as the problem rather than the illness as the problem which was the emphasis in other areas of the document.
4. There was no call for responsible journalism as there had been for the psychotic spectrum 'illnesses';
5. There was almost no emphasis put on early trauma and neglect issues for people labelled as having a 'personality disorder'; and
6. There was no gender comments or analysis.

I undertook to chase up these issues. I wrote a letter to the Health Minister, a letter to the Mental Health Branch and a letter to the College of Psychiatry. To their credit, the College Community Liaison Committee took up the issue immediately and engaged Russell Meares[3]. He was asked to totally revamp the section on personality disorders and the Commonwealth Mental Health Branch, pressured by the College, promised to replace this segment in the next edition. So I guess the outcome was good but it shouldn't have to be done like this. In this paper I will argue that as people with an interest in the way people labelled as having BPD are treated we need to form political coalitions to lobby and influence national policy with a longer term aim of being a real force to be contended with when deliberations start happening for a 4th National Mental Health Strategy in three years time.

Language:

I struggle so much with the language and I'm not all that sure that I have found an adequate solution to what I see as the massive problems with using the term, Borderline Personality Disorder. It was interesting to find out where the term came from as I did not realise that it was from of a psychoanalytic tradition with people being seen to be on the border between a neurotic state and a psychotic state. At the very least I think we should be letting people we have labelled in this way know something about the history of the term because without an explanation it is very easy to come to all sorts of conclusions about what it means. However, even beyond this the term is horrible.

I don't like labelling people. Full stop. However, I know that as an activist about half the consumers I speak to feel the gaining of a diagnosis is emancipating and the other half hate it like me. This tends to, but does not absolutely, follow the legitimacy and 'status'

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[3] A Sydney psychiatrist who specialises in self-psychology – a special form of psychotherapy developed for people who have been labelled as having Borderline Personality Disorder

of different categories of distress. Bi-polar Affective Disorder, for example, is one diagnosis that many people want to use because they think it makes sense of their 'madness' and also gives it a legitimacy that they are craving particularly if it has gone undiagnosed for many years. Borderline, on the other hand, tends to be one that people are really ashamed of and the shaming in the system which follows the diagnosis just intensifies some people's self hate in my experience. Persimmon Blackbridge, a Canadian consumer, wrote the following in her terrific book, Prozac Highway.[4]

> *"The main thing diagnoses are good for is sussing out what your shrink thinks of you – Bipolar Affective Disorder means they like you, Unipolar means you're boring, Borderline Personality Disorder means they hate you and Schizophrenic means you scare the shit out of them because they can't keep up with your thinking.*[5]

Several times at public meetings fellow consumers have asked me to take care when introducing them. Out of what can be many different labels they say things like; "mention I have been diagnosed with Schizophrenia and Depression but please don't say anything about Borderline." It is important that whatever we do we should encourage and to the best of our ability enable all consumers to use the language **THEY** feel most comfortable with. I just want to mention that some professionals see the act of naming yourself using psychiatric labels as 'wound identification'[6] and suggest that therapists should try and stop people from saying, "I am a Borderline!" From a consumer perspective this is both arrogant and silly. 'Coming out' as a nutcase in any way you choose to do it is, for us, a political and therefore very important statement that needs to be treated with respect.

For me, the getting of a Borderline diagnosis was a profound moment. From that point on everything changed including the language that was used to talk about me behind my back. Sometimes I joke about my file which I got through Freedom of Information. I was not surprised by anything and this has become my dearest line:

> *"You know all the horrible things you thought they were writing about you? They were! (and especially after I got a Borderline tag.'*[7]

So what's the answer? People argue that if we find another term this will just start to pick up the same mantle of hate as judgemental ideology gets transported from one label to another. Consumers argue, "can't we leave labels out of it altogether? What's wrong with treating us as distressed people?" This is a good question. I have spent many hours thinking about it and it wasn't till I went to a United Nations Forum on Older Women's

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[4] Blackbridge, P. 1997, Press Gang Publishers, Vancouver p. 32

[5] 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

[6] P57 Guidelines For The Treatment Of Borderline Personality Disorder In The New Zealand District Health Board Environment (unpublished) Mental Health Commission of New Zealand, 2004

[7] Especially after you 'become a Borderline' in their eyes.

Mental Health a few years ago that the politics of labelling things as ‘illness’ and ‘disorders’ especially within capitalist democracies really hit home. It’s about funding. Governments won’t, through dedicated health funding, fund something that just seems to be a disparate cluster of unrelated symptoms. You have to give it a scientific name, put it in a box and subject it to clinical trials before you can claim authority and therefore funding legitimacy.

In psychiatry there is the further influence of the American Psychiatric Association and the DSM IV[8]. Axis II diagnoses will continue to be the poor cousins whilst this document rules so much of our thinking in mental health. The somewhat curious relationship[9] between the American Psychiatric Society which produces the DSM and the American health insurance industry also influences the DSM profiles because the insurance companies are hell-bent on making sure Axis II diagnoses[10] remain there. This is despite the increasing evidence that:

> *“personality disorders, including BPD,… clearly meet the accepted (ICD[11] and DSM) criteria for ‘mental disorders’ and involve a level of distress and dysfunction comparable to Axis 1 conditions.”*[12]

So it’s not just that the label brings with it years of fear and professional helplessness within the system it has also carried the stigma of being ‘only Axis II’ and therefore not very important in the scheme of things. I will come back to this later.

Judith Herman, an American psychiatrist and someone who is greatly admired by many consumers, has called Borderline Personality Disorder a ‘sophisticated term of [client] abuse’[13] Consumers argue strongly that the best way to arrest the defamation that so often follows this label is to emphasise the very close correlation between adult experiences which get labelled Borderline Personality Disorder and childhood experiences of abuse and neglect. Herman’s ‘Complex Post Traumatic Stress Disorder’ is liked by many consumers for good reason. It makes sense to people and it draws appropriate and just attention to the role of childhood neglect and trauma in the development of such a condition. Others argue that that it is not useful because there are about 10% of people with this diagnosis who don’t have personal histories of abuse

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[8] Diagnostic and Statistical Manual of Mental Disorders

[9] Especially for people who don’t live in or particular understand American culture.

[10] personality disorders

[11] The International Statistical Classification of Diseases
and Related Health Problems, tenth revision

[12] 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

[13] Herman 1992 in Guidelines For The Treatment Of Borderline Personality Disorder In The New Zealand District Health Board Environment (unpublished) Mental Health Commission of New Zealand p. 5

and/or neglect.[14] Others argue that it needs to be placed within a spectrum of conditions that could be called ‘Trauma Spectrum Disorders’ (including Dissociative Identity Disorder and Post Traumatic Stress Disorder.[15])

My preference is to describe all of us as ‘people who have been labelled as having Borderline Personality Disorder’. I know this is a bit clumsy but it is useful for me because:

1. It suggests the naming language has emerged from the classification urges of the mental illness industry rather than from the consumer movement;
2. It offers recognition of the experiences of many consumers who cop a Borderline Personality Disorder along with another ten or so different labels as they make their way through mental health systems.
3. It questions the ‘thingness’ of BPD.
4. It registers my discomfort with medical language per se. and
5. It is what the consumer movement calls ‘people first language’, that is, the emphasis is on the whole person rather than on the illness/disorder.

This is the term I will use for the rest of this paper.

Medical hegemony through the eyes of a consumer and the influence this has on all thinking in the mental illness sector;

Consumers are divided about whether they accept a model of ‘brain disease’ or not. Brain pathology is the foundation building block for both psychiatrists and psychologists in relation to their understanding of consumer ‘symptoms’ and ‘diagnosis’. The more radical ‘survivor movement’ in the USA and the ‘user movement’ in Europe run a very strong critique of the brain disease model. There are Australian consumers who do likewise. In challenging the existence of ‘mental illness’ at all they extinguish the belief that Axis I diagnoses are somehow more legitimate and more important than Axis II diagnoses. If there is no ‘mental illness’ then it doesn’t matter if you’ve only got a disorder. One of the outcomes of this political position is that all forms of mental distress start to be seen as equally valid and equally deserving of society’s resources and the emphasis is on the distress and self determination rather than arguing about validity.

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[14] Guidelines For The Treatment Of Borderline Personality Disorder In The New Zealand District Health Board Environment (unpublished) Mental Health Commission of New Zealand p. 11

[15] Therapeutic Case Management for Borderline Personality Disorder (unpublished), Mental health Commission of New Zealand, 2004

The impact of the First National Mental Health Strategy[16] and the limited definition of the term, Serious Mental Illness (SMI) within this influential document;

The First National Mental Health Strategy was released in 1992. This coincided with the publication of Human Rights & Mental Illness[17] – the Report of the National Inquiry into Human Rights of People with Mental Illness.[18]

The principle concept that was used in both these documents was the idea of serious mental illness. This was not defined in either document. Over the next few years the strategy had enormous influence as National policy was developed and the policy and practice of State health authorities was strongly influenced by money from the Commonwealth being tagged to 'force' the States and Territories to conform with this new national agenda.

As part of this process of rapid change the term serious mental illness was, not surprisingly, appropriated by lobby groups and State bureaucracies within the sector.

> "*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."*[19]

Progressively it came to be known as Serious Mental Illness – a capital noun! Most often this got interpreted as meaning psychotic illness. At the time SANE Australia published a booklet; a *Guide for people with Mental Illness* which, in its attempt to be simple and reader friendly, literally stated that, "Serious Mental Illness means psychotic illness."[20]

The National Mental Health Strategy was criticised by people interested in a range of experiences other than psychotic illness. The Commonwealth Mental Health Branch defended its position claiming that in the policy documents and Mental Health Plan the emphasis was in line with The Burdekin Report and the term serious mental illness had never been officially defined as psychotic illness. As a consumer interested in these issues I was really keen to see what was happening at a local level. I collected pamphlets and publicity produced by Victorian services and studied carefully who they saw as their 'target' population. For a few years in the early 1990s Borderline Personality Disorder disappeared completely. When people labelled with BPD were included they were always the very last group to be included on the list and usually using language which

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[16] Commonwealth Department of Human Services and Health, *National Mental Health Policy*, April 1992

[17] Human Rights and Equal Opportunities Commission, Human Rights & Mental Illness – Report of the National Inquiry into the Human Rights of People with Mental Illness, Canberra 1993

[18] Commonly called The Burdekin Report as the Human Rights Commissioner at that time was Brian Burdekin.

[19] 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 p26

[20] To the credit of SANE I promptly complained about the misuse of these words and they changed the wording for the next print run but I think it was a really important 'slip' because it clearly articulated what consumers were feeling during this period and that was that without a psychotic label they were invisible within the system.

frankly stated that the only people of any interest to public services were people with extreme distress who were being a major problem for health services and the Victorian Mental Health Branch. The language was inherently judgemental emphasising the capacity for these people to disrupt services and providers rather than recognising any degree of suffering (either in the past or the present). I don't think this has changed. To read these pamphlets as someone who had been labelled as having BPD was really horrible and made me very angry. All of them made quite explicit assumptions about the relative worth and relative seriousness of different forms of distress simply based on what label they had attracted.

Towards the end of the First National Mental Health Strategy an evaluation was commissioned by the Australian Health Ministers Advisory Council (AHMAC)[21]. I was invited to be the consumer member on the committee. I was very excited about this appointment because I believed that it would give me a chance to 'talk up' the need for services for people with serious distress as adults because of neglect and/or abuse or trauma as young people. It just seemed such an obvious area of neglect to me that I got frustrated and annoyed when people started to call it, "Merinda's little issue". I am very aware that there was a mix of political forces happening here. One of the issues was to do with the fact that I was the only consumer on this committee and so therefore in some people's eyes 'not an expert'. The consumer movement is working very hard to try and turn this sort of ignorant arrogance around. The second political issue was that this jumped-up consumer was pushing for an issue that people in positions of power and authority wanted to shut their eyes about because:

1. They were scared of inundation if they were 'nice' to people with personality disorders;
2. It was a contended area and no one was feeling brave enough to approach it.
3. They didn't want to be seen to be not emphasising services for people with Schizophrenia, concerned that this would be interpreted badly; and
4. There was almost no effective political lobby at the national level for people labelled as having personality disorder' so there was no group I could use to (a) support me, and (b) refer the external evaluators to.

Other lobby groups were working very hard. It was difficult to ignore them because they often had sector leaders driving them or the potential to make a media fuss.

It would have been impossible to have completed the evaluation without drawing attention to the absence of a definition of serious mental illness.

> *" In the absence of an authoritative definition of priorities, terms such as these will be subject to local interpretation. Unless defined, they are incapable of being audited to ensure that service rationing is conducted in an ethical manner"*[22]

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[21] 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

[22] 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 p 26

The recommendation was therefore made that:

> *"…a national definition of service priorities should be developed that takes into account clinical diagnosis, personal functioning and suffering."* [23]

I was unhappy about this because:

1. I didn't (and don't) believe diagnosis should be the first priority in determining 'need';
2. I have always hated the 'personal functioning (high function; low functioning) arrogant discourse; and
3. I argued then that if the discourse and documentation had till this point of time been absolutely silent about the 'suffering' of people with BPD (and not sophisticated enough to factor in the suffering from childhood) how could we possibly convince people of the real needs of this group.

Outnumbered and outgunned, the evaluation reflected the values of others rather than me. The results of the lobbying and other political activity of other groups became obvious with the publication of the Second National Mental Health Strategy which moved the emphasis on to such things as prevention; suicide; and 'high prevalence disorders' such as depression and anxiety. Influential sector leaders such as Gavin Andrews argued very strongly for these changes in emphasis. There was not one reference to people with any of the trauma spectrum 'illnesses'. I was frustrated.

The Third National Mental Health Strategy followed on from the Second. It's not a very inspiring document really. Even though the First National Mental Health Strategy was controversial and flawed it was very strong on consumer participation and very exciting in terms of making gutsy changes to some of the taken-for-granted assumption of the 'mental illness establishment'. The sad thing for many of us is that the Second and Third Strategies have been bland and mostly unexciting. People and organisations who represent people with psychotic illness were angry. They had seen the gradual seeping away of the advantages that had come to them with the First National Mental Health Strategy. As a result of this there is now a re-channelling of community energy into lobbying for emphasis to go back onto 'low prevalence disorders'.[24] They will, no doubt, try very hard to apply political pressure when and if this Strategy is evaluated and a Fourth Strategy is mapped out.

I am angry that through out these Strategies the issues for people with trauma spectrum distress has never even got a serious mention. Despite me sitting on the Steering Committee for the Evaluation of the First National Mental Health Strategy it was still invisible. For many people labelled as having BPD this total invisibility and neglect by

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[23] 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 p 27

[24] This is the term that is being used instead of serious mental illness this time around. I have tried to find out whether Borderline Personality Disorder is included in the category of low prevalence disorders. Most commentators I have asked seem to think it is not.

the system perfectly resonates because it crudely reflects the way they were treated as children.

The competition that consumers observe between different professional groups and proponents of particular methods as they vie for power and territory;

Consumers are perceptive. We see the discord not only within teams of professionals who might be working with us but also within the academic debate and the political manoeuvres that we see around us. I personally find the idea of 'splitting' quite amusing because from my experience it would seem that professionals in this area don't need my assistance to help them disagree with each other!

In 1999 the Commonwealth funded a very interesting series of weekend workshops.[25] They were attended by representatives of the umbrella organisations for each of the discipline groups that play a major role in servicing the mental health sector: mental health nurses, psychologists, psychiatrists, occupational therapists and social workers. Also invited to these workshops were a critical mass[26] of consumers and a critical mass of carers. The consumers and carers had a chance to meet in Canberra on their own before the representatives of the disciplines got a chance to attend. This was done deliberately in an effort to enhance the less powerful voices of consumers and carers. These series of workshops were terrifically inspiring. In the early workshops there was tension. Representatives of each of the professional groups got a chance to meet together but always with a consumer and a carer present to observe the discussion. In the early days there was a tendency for each of the groups to feel hardly done by and misunderstood. There was also a tendency to use humour to have a go at other professional groups in the sector and to feel 'unheard' and misjudged by consumers and carers. [27] It felt to us, consumers, as if it was defensive as each group tried desperately to mark out its territorial expertise.

The most interesting thing that happened however was that as these workshops progressed this funny defensive humour was slowly replaced by the realisation that the consumer body of expertise (the lived experience of mental illness) was actually as important as each professional group's accumulated wisdom. Many professionals who experienced these workshops tell vivid stories of how they were challenged and how they changed through the experience. Several people went back to their home cities and proceeded to initiate projects and programs which came directly out of their learning in

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[25] Deakin Human Services Australia with funding from the Commonwealth Department of Health and Aged Care; Learning Together – Education and Training Partnerships in Mental Health, February 1999

[26] critical mass is the size or amount of something [consumers and/or carers] that is required to enable their voice to be adequately heard. See opposite – tokenism.

[27] And we did point out that these feelings of being totally misunderstood, misrepresented and invisible were pretty familiar to us!

Canberra. Some consumers came away feeling that, at last, we were involved in a way that was not just tokenistic.

But nothing is perfect. The glitch came when those who attended these workshops went back to their constituencies (including Australia-wide professional organisations) and tried to influence the internal politics within these organisations. There was very little success. The importance of this for me is that as a consumer activist I am now more respectful of the conservative pressure being applied be discipline representative bodies

n I mention these workshops here is that they modelled a way to bring together all the people with an interest in the professional education of the mental health workforce. They modelled a process where there was not just one tokenistic consumer but rather a group of people who, by the time the workshops started, knew each other. And most important of all they proved that coming together to try and achieve something actually works.

It seems to me that getting issues for people labelled with BPD up nationally **is more important** than anything else. My experience has proven to me that I can't do it on my own and I have found over the last fourteen years that there is no organisation or group that I can turn to for political support. There well might be sub-groups that form part of professional organisations but these have never been accessible to me because professional organisations tend to look inwards rather than outwards. Wouldn't it be great if a group of us (covering all the professional groups who are involved with this area and absolutely regardless of specific methods (provided that they are things that are ethical and working[28]) join forces with consumer groups to fight for national acceptance of our legitimacy and importance.

The consumer and carer movements[29] in Australia and discrimination against people who are 'out' about a diagnosis of Borderline Personality Disorder;

I also want to speak a little bit about the issues that confront us from the point of view of the organised consumer and carer movements in Australia.

Survivor politics[30]/consumer politics

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[28] Dialectical Behavioural Therapy (DBT) seems to have clinical and research support. I'm not sure if it has consumer support. Self-psychology has my shrink's support and this counts for me! It also has support from the work done by Russell Meares in Sydney and an extensive and well documented scientific trial.)

[29] I have on occasions argued that the politics around BPD is about fifteen years behind the politics of psychotic illness. This is due to a number of things including the absence of a political campaign by consumers and carers.

[30] The word 'survivor' is used differently in Australia than it is used in America and some European countries. In Australia it is generally used to describe people who recognise themselves as survivors of childhood abuse. In the US it is used to describe people who see themselves as survivors of the Mental Health System. It is the more radical arm of the mental health consumer movement in these countries.

Groups which one would assume would have the same or similar political agendas sometimes don't.

Survivor politics in Australia is about people who have survived childhood abuse joining together to form a lobby group to pressure governments about policy and practice especially in relation to childhood abuse issues. These groups tend not to emphasise adult malaise brought about by these childhood events and they especially don't want the general public making an assumption that childhood abuse equals adult mental illness. There is no good reason why people who have been abused as children would have any less a stigmatised view of mental illness as anyone else. They often don't want to be affiliated with others who are striving to claim the authenticity of these links. Even when people who see themselves as survivors in this sense experience adult difficulties the last thing that they may wish to be labelled is 'sick". [31]

On the other hand consumers who have been labelled as having BPD and are attempting to make their way as best they can through mental health services have political needs that are completely the opposite. We need to be accepted as 'genuinely deserving of services and within a model of understanding distress that privileges brain disease we have to claim 'dis –ease' as loudly as we can. We might want to critique the 'distress is disease' model of understanding of emotional distress but as I have mentioned previously this jeopardises possibilities of funding and further alienates us from the places where real decision-making about policy priority is being made.

The differences between the organised consumer movement and the organised survivor movement divide people who have similar experiences and split the potential for effective combined lobbying.

Mental Health Consumer Politics

There are a few issues that influence our capacity to get issues for people labelled as having BPD up as important aspects of the consumer political agenda.

1. There is discrimination within the consumer movement itself. Sometimes we don't want to face some of these issues but the reality is that whilst legitimacy is seen to go with psychotic illness or other Axis 1 diagnoses some other consumers will continue to see our issues as aberrant;
2. Consumers are no less influenced by the 'mad'/'bad' dichotomy as anyone else. Many consumers distance themselves from people who are labelled as having BPD because they believe that in some way collective political lobbying will put back the agenda that 'madness is not badness'.
3. The disputes around language are very real. There is important work we need to do internally (within the consumer movement) before we can launch a broader political campaign.

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[31] "This is not an illness! It is not my deficiency. It is what was done to me and I will not accept that it has anything to do with the medical system. What we need to do is catch more perpetrators/support people who disclose/ keep a sustained attack on the Catholic and Anglican church etc.

4. Whilst many of us remain cynical that there is even such a thing as BPD and others recognise the political reality that we have to name it to lobby successfully there will be tensions within the consumer ranks. The pragmatists tend to have a different agenda from the ideologues.
5. Some consumers have been frightened by the way people labelled as having BPD have demonstrated their distress. Self-harm can be quite frightening for others to witness particularly if it is in an acute unit and you are already having a rotten time yourself.
6. Consumers pick up on all the subtle messages being put around by the system about how undeserving people who have been labelled as having BPD really are. It should not surprise us that these attitudes follow them into the consumer political arena.
7. BPD is a label that is mostly attached to young women. Mental health consumer politics is often beset with power issues which include issues related to gender. It is understandable that 'women's pain' might be seen as less important and less worthy by those men whose experience does not include anything at all resembling the issues for women labelled as having BPD.
8. Many consumers associate BPD with criminality. They see women rotating between drug and alcohol services, mental health services and forensic services. They then distance themselves from people in prison by distancing themselves from people labelled as BPD.

Mental Health Carer Politics

Over the last fifteen years the carer movement has grown substantially and gained increasingly more power. Several high profile carers have been appointed to positions of enormous authority and power within the sector.[32] Corresponding promotions to positions of such authority have not happened for consumers. There are some important implications of this:

1. The carer movement tends to almost exclusively represent people (mainly parents) of people with psychotic illness.[33]
2. The issues for parents with children with psychotic illness are often very different from the issues for consumers labelled as having BPD.[34]
3. Issues of childhood neglect, trauma and abuse are an anathema to many carer organisations who work very hard to maintain the 'new' (unlike the 1970s) attitudes which no longer blame parents for their children's mental illness. This is fundamentally at odds with raising issues for people labelled as having BPD into a strategic position on the political stage.

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[32] For example, John McGrath, an ex-politician who was the inaugural Chair of the Mental Health Council of Australia. He was followed by Keith Wilson. Both are ex-politicians and fathers of children labelled as having Schizophrenia. .

[33] I have some ideas about why this might be the case and I think one of the realities is that middle class professional 'fathers' experience an enormous shock when their sons and daughters have to experience public health systems. Given any other circumstance they would have the purchasing power to buy private health experiences but if their son or daughter is sectioned under the Mental Health Act they have no choice.

Second Story

There is a little story I sometimes tell and it involves a forum that was organised to bring Victorian consumers and carers together to talk about some of the issues that had come between them and to work out ways of moving forward together.

When we broke into small groups I was allocated to a group which was convened by a very influential father of a man with Schizophrenia. In this group there were two young women who bravely ‘came out’ as having been labelled BPD. When they got a chance to speak they talked about the fact that the very nature of their childhood backgrounds meant that their parents couldn’t care less about them let alone want to be involved in mental health politics. They suggested that this might be a very common scenario amongst people who have been labelled as BPD. Thus, they argued, the key agenda item for them was to wrestle power away from Carers whose only experience was with psychotic illness and to influence the agenda sufficiently to get issues for trauma spectrum consumers taken seriously. This invisibility, they explained, had left them cynical and disillusioned about consumer/carer politics in Victoria.

The very interesting sequale to this discussion was when our small group’s discussion was fed back to the plenary (by the carer who was chairing it) he made a decision to ignore this entire part of the discussion suggesting that some members of the group “weren’t quite clear about the task they had been asked to do”. He then spoke at length about issues of confidentiality and privacy which was the issue that many people (especially carers) with experience of children with psychotic illness had chosen to emphasise.

As usual, I wrote a letter to this influential carer and pointed out to him what I had observed during that forum. He didn’t reply.

The unintended consequences of State Mental Health Acts[35]

> *“The vast majority of involuntary patients in Victoria are admitted and detained as involuntary patients because their mental illness meets the criteria for mental illness as defined by the Act.”*[36]

In setting criteria for involuntary detention clauses have been added to minimise any possibility that the ‘wrong’ people could be trapped under the Act. There are several

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[35] For the purpose of this discussion I will refer to the Victorian legislation, The Mental Health Act 1986, however, I think that some of my arguments may well be relevant in other Sates. However, the significant difference between Victoria and other States and Territories is that we do have Spectrum (the State-wide Borderline Personality Disorder Service). Consumers around Australia are very aware of this and want a Spectrum too!

[36] Mental Health Legal Centre, Patients’ Rights – A self-help guide to the Victorian Mental Health Act, May 2003

arguments about why this has been done and they include the knowledge (and the latest evidence including from Spectrum) that some people have problems that will get worse if they are admitted to hospital especially for long periods and especially involuntarily. However of equal importance is the attempt to protect those who are 'just' loud, or eccentric, or different or who have strong beliefs and proselytise publicly etc. from being swept up into involuntary admission by The Act.

The first criterion for involuntary admission is that the person concerned appears to be **mentally ill** as defined by the Act:

> *"'Mental disorder' includes 'mental illness', plus a range of conditions which are not mental illness for the purposes of the Act. Some mental disorders, such as personality disorders, are not "mental illnesses" under the Act and cannot usually be the basis for involuntary treatment."*[37]

On face value especially to consumer eyes this looks like its good for people who have been labelled BPD because who wants to be locked up against your will, secluded and treated with force? However, there are some interesting anomalies that come out of the way The Act is interpreted.

1. It is extremely difficult to argue that a group of people who are not deemed to be 'mentally ill' under the Act are still a group with substantial and legitimate needs in the system. With the everyday shorthand use of the term 'mental illness' to describe the target population of everything people who aren't mentally ill (in terms of the Act) can easily get left out;
2. Although we have supposedly had our institutions deinstitutionalised this is not the whole truth. The mental health system is still a system and its epicentre is the acute unit. Consumers know this:

   > *"the life of the [Understanding & Involvement] Project (U&!) coincided with a process of 'deinstitutionalisation in Victoria and funds were moved rapidly from acute services and into what might euphemistically be called 'community' settings. Despite this change of focus, consumers were adamant in insisting on the U&Is direct reference to acute settings."* [38]

   The political reality is that the mental health system still uses the metaphor of 'the bed' to work out how it will distribute resources. The usual induction into a public service is through a stay in an acute unit. People go from an acute 'bed' to backup community services. So, those disorders (not illnesses) which are seen to not 'deserve' 'beds' will, unintentionally perhaps, be disadvantaged in a system which relies on system-determined need criteria to distribute resources. This will be the case

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[37] Mental Health Legal Centre, Patients' Rights – A self-help guide to the Victorian Mental Health Act, May 2003 p.5

[38] Wadsworth Y., The Essential U&I – A one-volume presentation of the findings of a lengthy grounded study of whole systems change towards staff-consumer collaboration for enhancing mental health services, Victorian Health Promotion Foundation 2001 p iii

except when the system and services are put under an enormous amount of pressure by specific individuals who can not be ignored.[39]

The hidden stigma within some of the organisations that are leading the way in fighting stigma and informing the national debate about mental health issues.

Finally I would just like to mention the role in national politics of organisations such as the Mental Health Council of Australia (MHCA) and SANE Australia.[40]

SANE Australia

SANE Australia advertises itself as being able to provide, "everything you need to know about mental illness…[41] I have had an ongoing discussion with SANE about what I see as the invisibility of BPD on their website and in their publications. There is a Fact Sheet on BPD. It is the second last one on the list coming down from the top. Psychosis is on the top of the list followed by Schizophrenia and then Bi-polar Affective Disorder. The reader is left in no doubt about SANE's priorities and the way they have chosen to order importance.

I have taken the opportunity to compare the general tone and language in this Fact Sheet with the corresponding Fact Sheet on Schizophrenia. In the Fact Sheet discussion of Schizophrenia people are described as living with, '… a prolonged illness which can involve years of distressing symptoms and disability". I have absolutely no argument with this, however, in the corresponding first paragraph on the Fact Sheet for BPD there is no emphasis on distress; rather, the whole emphasis is on people learning to manage their behaviour successfully. I hate this. The behaviour is as a result of something. It doesn't just jump out from nowhere. This is grossly unfair and judgemental.

This is followed by one inadequate paragraph about, "what causes BPD." I think that this is the bit that annoyed me the most because we **KNOW** that there are very real links (for most people) between childhood neglect, trauma and abuse and adult onset of 'BPD'. This is exactly the part where there was for most of us awful suffering, neglect and trauma. The reality is that mental distress is real and awful regardless of the label that is attached to it or its proximity to a neat definition consistent with a medical model understanding of 'illness'.

SANE has explained to me that there are genuine reasons why it has concentrated less on BPD:

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[39] This argument is less effective in Victoria, thank goodness, because of the role Spectrum plays.

[40] These are just examples. I am not suggesting that the invisibility of Borderline Personality Disorder is only to be found in these organisations.

[41] See website at http://www.sane.org/

1. Individual resources are funded using money that comes from specific business interests or other benefactors and SANE has failed to attract anyone to bankroll a publication on BPD[42];
2. It is not a matter of intrinsic worth but rather one of the priority of the organisation's Board[43];
3. Borderline Personality Disorder is already adequately covered in the SANE publications.[44]

I have always been respectfully listened to by Barbara Hocking[45] and I think we appreciate each others' differences and point of view but it's just that I have seen no real change in the organisation's priorities or modus operandi. I do not agree that issues for people labelled as having BPD (which are respectful both of people's adult lives but also of their childhood trauma and neglect.[46]) are adequately dealt with by SANE. One of the things that I would like to do is to bring a group of people together to meet with SANE and to drive a new publication. This consortium would include consumers, carers, professionals interested in issues for people labelled as having BPD, interested community groups and anyone else who states an interest in being involved.

I also have some issues with SANE's anti stigma campaign. I put forward these suggestions realising that overall I think SANE have done a good job in bringing issues of stigma and discrimination into the public consciousness. My reservations are these:

1. There seems to be an over emphasis on men and the portrayal of violence and psychotic illness. This is not very useful for a group of consumers who are much more likely than not to be women.
2. There has been much less emphasis by SANE on discrimination in the sorts of institutions that young women labelled as having BPD are likely to get entangled, including forensic services, community services and family law institutions.
3. The SANE website emphasises stigma against people who have 'mental illness' which, unintentionally I would think, de-emphasises the plight of people who do not fit into a neat definition of 'mentally ill'.
4. The most important anti-discrimination knowledge that many people who have been labelled with BPD want to get out to the public is that their 'behaviour' comes from somewhere – it is not badness. It is more likely to be as a result of

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[42] The obvious thing that comes first to mind is that drug companies would have little or no interest in funding projects for SANE that primarily address issues for people labelled as BPD.

[43] Which is well known for including some eminent business people and others who might be expert at raising money and raising the profile of mental illness but who might not really understand the need for all people with mental disorders to be authentically represented in the publicity, the stigma campaign and the information books and booklets.

[44] When I ran a word search I found that Borderline was mentioned and I have noticed that the invisibility that was there a few years ago is not so apparent recently. However even a cursory look at the published material shows that very few of the publications are specifically for people who have been labelled as having BPD and none, to my knowledge, has been written by people who have been labelled as having BPD. Most references appear as part of a discussion about 'proper mental illness'.

[45] The Executive Director of SANE Australia

[46] I suspect that this issue of the relationship to childhood neglect and trauma which might make it difficult for SANE to approach this area because SANE, like other influential notional bodies, has a strong carer base.

the badness of others when they were young. Protecting adult perpetrators and/or negligence is a form of discrimination. Portraying a false picture of consumers' early lives as unquestionably rosy and pure is also discrimination. We would like to challenge SANE to act responsibly and take on these issues.

5. The campaign largely fails to take up the issue of discrimination within mental health systems themselves. Consumers often report that the worst discrimination comes from inside services and is particularly targeted at people labelled as having personality disorders.

> *"A new kind of stigma has emerged within mental health services. It relates to legitimacy: the mark of infamy is not now that of being 'mad' but rather of not being 'mad'. Consumers have described how the label given to their distress has a great bearing on the way in which they are treated in services… During a consumer-run education session. A service provider was asked, 'What would be the worst thing that could happen to you if you were in the system?' One provider's instant response was, 'to be diagnosed as borderline or antisocial personality disorder'".*[47]

Mental Health Council of Australia (MHCA)

The MHCA claims it is the independent, national representative network of organisations and individuals committed to achieving quality mental health for everyone in Australia. It is progressively becoming more and more politically influential as it is favoured as **The Voice** of the sector by the Howard government.

In some ways the MHCA simply reflects the political lobbying power of its constituent member organisations. Therefore, we shouldn't be either surprised or too critical of the fact that it has thus far not engaged publicly (that I know of) in promoting issues at a national level that are of central importance to those of us who care deeply about people who have been labelled as having BPD. In many ways it is a reflection of our own incapacity to organise ourselves into a coherent public voice and demand representation on the MHCA Board.

MHCA affiliated organisations, the MHCA secretariat, the MHCA Board and the Executive have rarely (to my knowledge) sort to elicit the specific consultation expertise of people who have been labelled BPD and the professionals who work with us. As we are a minority within the mental health system we have to be strategic but the Board of the MHCA, consumer organisation affiliated members, professional groups and all the other players have to be responsive to our issues and we need to make sure they take this responsibility seriously. I know this is not easy. I have tried; firstly with the National Community Advisory Group on mental health (NCAG) which was set up to directly advise the Commonwealth Minister of Health and then with the Australian Mental Health Consumer Network which has a seat on the Board of the MHCA and which had up until recently a seat on the MHCA Executive. Despite my proximity to the powerful

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[47] Epstein M. and Olsen A. Mental Illness: Responses from the Community in Mental Health in Australia-Collaborative Community Practice edited by meadows G. and Sing B., Oxford University Press 2001 p. 17

players at a National level I have largely failed to influence anything very much. However, I am still convinced that if we all join forces and quit operating in enclaves we will experience much greater political success.

World Mental Health Day

The other issue I want to briefly mention is Australia's efforts for World Mental Health Day for 2002 and 2003. The World Federation for Mental Health[48] is responsible for introducing a theme for World Mental Health Day internationally each year (October 10th). In Australia the national responsibility and funding for organizing State based functions is held by the MHCA.

The theme for each World Mental Health Day comes from the World Federation with some resources. In 2002 and 2003 the theme was: *The Effects of Trauma & Violence on Children & Adolescents.* I was inspired by this and I immediately contacted the Mental Health Council pleading with them to be careful how they interpreted this and urged them to be mindful of the needs of people who have adult mental health problems because of issues of trauma and violence as children. I was aware that you couldn't just emphasise people with BPD. The fit wasn't that good. But, it was a chance to, at last, get some of these issues thought about by the community. Each theme runs for two years so I suggested to the MHCA that they might think about emphasizing the issues for children when they are children during 2002 and then look at issues for adults who were traumatized as children in the second year.

Unfortunately I could not get a strong enough political voice behind me. I don't think I even got a reply to my letter. What happened was that the MHCA came up with an Australian slogan for the theme. It was, "Less tears. More cheers" and focused mainly on bullying in schools. To me this felt trite and irresponsible. I hated the slogan and so did many others. In my opinion this was a perfect opportunity that was completely wasted. Consumers were understandably angry although a lot of them now don't expect it to be any different. It was in the light of this that I became particularly concerned that we haven't organized ourselves politically. With the MHCA growing and becoming even more influential I think we need to develop a national organization (with member organizations in four of the State and Territories (as I think this is a prerequisite in the MHCA constitution) and become a member. Everybody else seems to be and I can't think of any other way to influence the debate.

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[48] (http://www.wfmh.org/) The World Federation for Mental Health is the only international, multidisciplinary, grassroots advocacy and education organization concerned with all aspects of mental health.

Conclusion

The population prevalence of Borderline Personality Disorder in Australia is approximately 1%[49] . This is similar to the population prevalence of Schizophrenia. [50][51] Both of these disorders are disabling and serious. Both have high rates of reported suicide. And yet, there is no comparison between the ways these two disorders are understood in the sector or 'sold' to the public by the sector. Within the sector Schizophrenia is seen as tragic, difficult but absolutely legitimate[52] and 'BPD' is seen as difficult and a pain in the neck (and the public purse) – to be avoided except for those individuals who, quite literally, can not be avoided. I am not arguing that we should be vying with Schizophrenia for scarce mental health resources and the public imagination; rather I am saying that those of us who are vitally interested in the lives of people who have been labelled as having Borderline Personality Disorder need to influence the public and thereby the Government to see all the different forms of emotional distress as worthy of resourcing and priority. This will not happen unless we get ourselves organised and both learn from and educate successful organisations such as SANE and the Mental Health Council of Australia (MHCA). It is only by joining respectfully together and picking up the political cudgels that we will ever become a real force in the national health debate.

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[49] Henry Jackson & Philip Burgess' 2000, *Personality Disorders in the community: a report from the Australian National Survey of Mental Health and Wellbeing*

[50] 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

[51] Jablonsky A. et.al *Psychotic Disorders in urban areas: an overview of the Study of Low Prevelance Disorders in Australian and New Zealand* Journal of Psychiatry 2000;34: 221- 236

[52] Please note that many consumers (especially those who may have been labelled as having Schizophrenia) find this is an oppressive, hopeless and unacceptable way to be viewed.