

## **THE EMPEROR'S NEW CLOTHES: ON BEING INVISIBLE AND NEGLECTED WITHIN THE MENTAL HEALTH SYSTEM--A GENDERED PERSPECTIVE FROM A "BORDERLINE PIONEER".**

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### **ABSTRACT**

*Since the publication of the First National Mental Health Strategy in 1993, Australian mental health policy has prioritised services for people diagnosed with psychotic illness. There is unanticipated fallout from this approach. Certain groups of people are systemically locked out of services through a justifying rhetoric that denies the seriousness of their distress. This paper looks at the vulnerability of women labelled as having Borderline Personality Disorder (BPD) to this approach and this rhetoric. It looks at the use of the Diagnostic and Statistical Manual (DSM) as a political tool and the systemic, diagnosis-based discrimination within services, as well as hierarchies of legitimacy and shame. How does a fight for people's right to 'be seen' sit within a consumer<sup>1</sup> critique of psychiatry's apparent thirst to create more and more categories of pathologised person? This paper names the 'borderline' dilemma as a gendered issue. It also names it as a socially constructed one located in the politics of childhood trauma.*

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### **INTRODUCTION**

When I made the significant decision to 'come out' publicly as a 'BORDERLINE' my shrink was horrified. She swivelled around in her very creaky chair and asked aghast, "What do you want to talk about that diagnosis in public for? You've got a perfectly good psychotic diagnosis to use in public!"

A few months after this I was doing some research and I found that some psychologists have come up with a phrase intending to pathologise the legitimate political activity of people who have been given a diagnosis of 'borderline'. Apparently calling myself a 'BORDERLINE' in public is now understood by some as 'wound identification' (Wilson, 1998) and I'm to be discouraged from doing it!

Despite these attempts to dissuade me I will continue to talk about my own experiences and I will continue to raise public awareness about the experiences of other women who are labelled<sup>2</sup> as having Borderline Personality Disorder. I believe that to not do so would be negligent, as it would add my silence to the neglect and invisibility that for so many in this group started in childhood.

### **FIRST PERSON VOICE<sup>3</sup>**

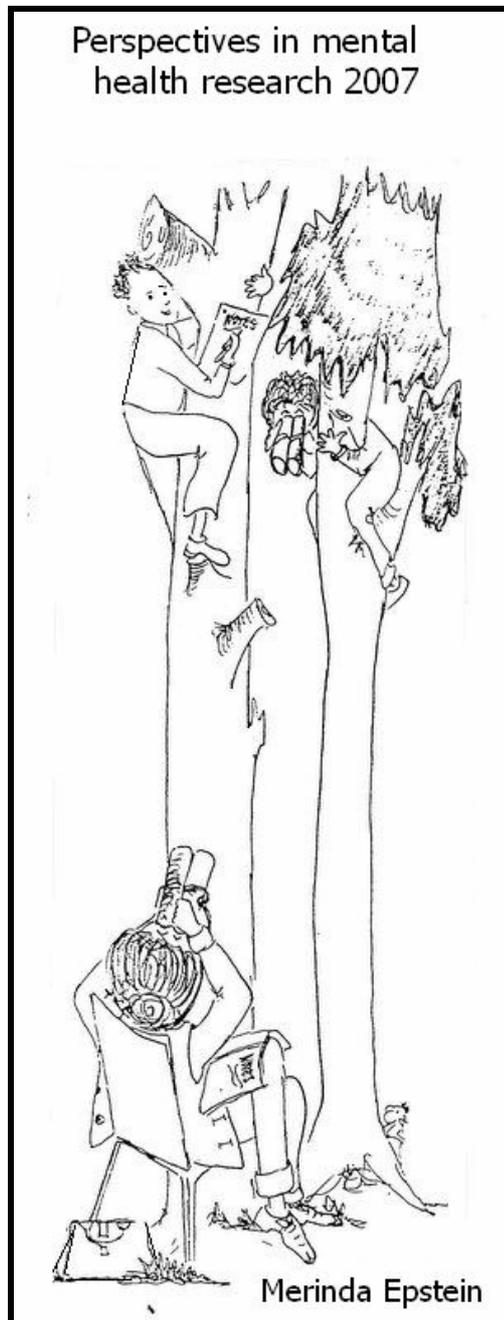
I will be presenting this keynote from a consumer perspective or from what is known by some as the first person voice. By choice I will refer to consumer literature where I can, although this is hard to find because most of it is in the category of 'grey' (or unpublished) work and cannot be sourced through traditional search engines or through most mental health libraries.

It is crucial that I use this keynote in part to debunk the myth that the first person voice is 'unscientific' or 'non-rigorous' and therefore offers less important knowledge than the third-person voice<sup>4</sup> in debates about mental health representation, sector planning, and evaluation.

David Webb, a Melbourne based consumer writer, who has recently completed his PhD on suicide and spirituality (2006), has made a significant contribution to our thinking about first person voice. He argues that there is a sound base in the theoretical work done in the discipline of consciousness studies and refers us to the work of David Chalmers (2004). In his important article, 'Bridging the Spirituality Gap' (2006), Webb presents a compelling argument that we will never totally comprehend what is needed to adequately understand mental distress until we ask the people who experience it<sup>5</sup>. From such a perspective service planning, for example, must be firmly based on the knowledge that comes from the subjective, which is often phenomenological, or the 'I'/'me' understanding of reality not re-told or re-interpreted through the prism of the professional or distanced 'other'. As well, we need to understand the inter-subjective, which is often anthropological in nature, or the 'we'/'us' understanding of survivors/consumers told through

our shared understandings and once again not re-interpreted through the experience of the ‘other’ (often so-called ‘independent’) clinician or commentator.

These arguments also apply to research methods. Consumers can do ethical and critical<sup>6</sup> research from this perspective and can also critique the ethics of the research of the ‘other’ (often politically constructed as the ‘independent researcher’) from this perspective. There are a number of research methodologies that are consistent with first person research but it is difficult to access funding for any of them in this country.



My own background is in Participatory Action Research (PAR) (Wadsworth & Epstein, 1998; Wadsworth, 2001) where a group of consumers, sometimes with the help of a methods advisor, combine the first person theoretical perspective with research/evaluation techniques that are essentially action oriented, demanding change and not just reports to sit on someone’s bookshelf.<sup>7</sup> This is a dominant and respected method in many countries particularly in the developing world but it is often scoffed at as ‘unscientific’ (usually meaning less prestigious) within the tradition of health research in Australia and other so-called ‘developed’ countries. The fusion between experience, science and politics is central to

my argument in this paper regardless of whether I am talking about the politics of gender, class, first person voice, health promotion, mental health policy development, or service delivery priorities. My commitment to the importance and power of the first person voice grew from my experience of feminism in the 1980s. I will argue here that 'Borderline Personality Disorder' is fundamentally a gendered issue in mental health politics.

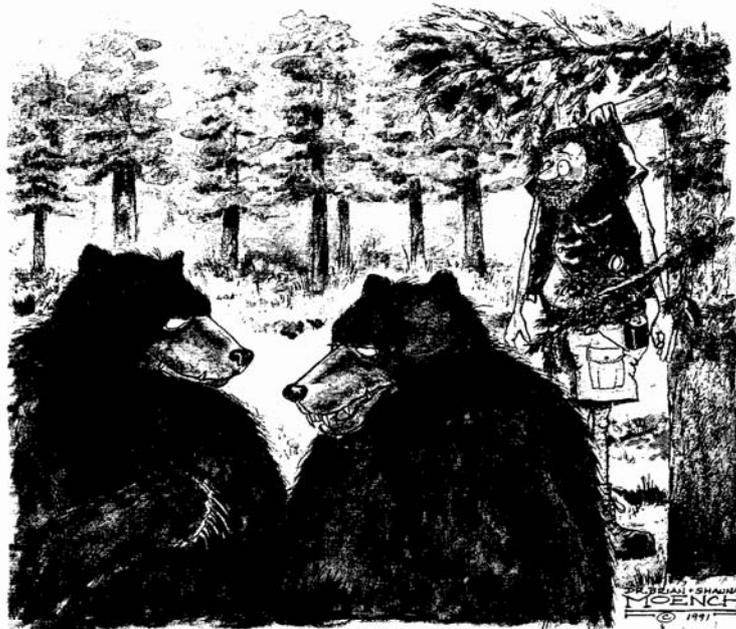
*Feminists and mental health activists have many overlapping concerns, as well as sometimes common identities, and we can learn much from our diverse histories. We know that our differences can enrich debate and extend our strategies for change, but only if we give up believing that we are always right. We can never speak for everyone. Nevertheless, making links between personal experience and political enterprise opens up the landscape of recovery because it makes individual misery a fully social issue. It's no longer about disordered personalities, for example, but about social relationships, both past and present that shape who we are and what we do. (Warner:2004:32)*

## **GENDER AND LANGUAGE**

Throughout this paper I will refer to people who experience 'borderline' as women. For those who are unfamiliar with the diagnosis it is important to recognise that between 70% and 95% (depending on different methods of collecting statistics) of people who receive this diagnosis are women (Grey, 2006). I use gender specific language intentionally. Gender is significant and to ignore it is to add a further layer of invisibility to an already marginalised group. This does not mean that men don't receive this label and that they, too, don't suffer from doing so.

### **"PIONEER CONSUMER ACTIVIST"**

I received a card<sup>8</sup> from a fellow 'mad folk'<sup>9</sup> which I have adopted as my maxim for this keynote.



*"His name's Bradshaw. He says he understands I came from a single parent den with inadequate role models. He senses that my dysfunctional behaviour is shame based and codependent and he urges me to let my inner cub heal ..... I say we eat him."*

Inside the text reads: 'A little food for thought'

Her black humour is of no surprise to me but perhaps the accuracy of her sentiment in capturing exactly what I want to try and do today surprised me a little.

I don't want to give any sort of authoritative account of 'Borderline Personality Disorder' (BPD), although I might have to say a bit about what it is thought to be so that those of you who are unfamiliar with the diagnosis will get a bit of an idea.<sup>10</sup> But this is a consumer keynote and I don't want to get stuck on clinical debates.

What I do want to do is to raise our collective consciousness and give us all some *food for thought* (although not by literally eating the psychotherapists in the room I hope) not just about 'borderline' as a diagnosis but also about the nature and limitations of psychiatry--touching on issues to do with psychiatric imperialism, gender, childhood abuse and trauma, diagnostic hierarchies and health politics. Sometimes this will be challenging and it is tentative because there are still internal contradictions in my argument and places where I am simply putting in a plea for more 'Deep Dialogue,'<sup>11</sup> prioritising collective conversations where there is a critical mass of consumers --particularly and especially consumers who have something important to say and a profound interest in this label-- while recognising that conversation might be a way of proceeding that comes more naturally to women.

Discussing and critiquing policies about resource allocation priorities and the linguistic gymnastics that are needed to support resourcing decisions when there are finite resources and much politics is always fraught, and assertively raising the matter of gender is, I know, out of fashion. However, we need to do it. A friend in the consumer movement teased me the other day about my preoccupation with language. I make no excuse for this. I have seen many people as hurt by the rhetoric as they have been by the failures of the system. For example, I regard the words 'just' and 'only' as very harmful within the patriarchal discourse of mental health service priority setting as well as in mental health practice. They are often ascribed to pain or distress that does not have the status of illness (eg. just a 'borderline'). They are terms frequently used to describe self-harm when it is compared to the so-called 'real suicide attempt'. Women, we are told, are statistically much more likely to self harm in ways that bring them in contact with the mental health system and, of course, self harm and its complex internal meaning systems are significant in any discussion about 'borderline'. No one has the right to dismiss another's distress as 'only' or 'just' anything. When this is done routinely and systemically to women who were often invisible and dismissed as children it constitutes abuse.

At the consumer day someone asked me whether my reference to the Emperor's New Clothes in the title of my talk was an indicator that I was going to present in the nude. Fortunately for you this is not the case though I'm open to improvisation from the floor if anyone feels so inclined. In the meantime I want to correct a typographical mistake in the title of my paper in the conference program. It is an important one for me. It should read, "*The Emperor's New Clothes: On being invisible and neglected within the mental health system: a gendered perspective from a 'borderline pioneer'*". The term 'borderline pioneer' should be in inverted commas. I'm uneasy about calling myself a 'pioneer' in this area. Felicity Grey's terrific paper (2006), which includes some interesting insights into the history of the diagnosis, paints a fascinating trail from witches through hysteria and psychoanalysis's frustration with our apparent 'untreatability' leading on to this idea that diagnostically we don't fit clearly into either the category of neurotic illness (depression or anxiety) or that of psychosis. We are somewhere in-between and hence, **borderline**. So, a lot had gone on before I appeared anywhere near the scene.

What I was trying to convey in this term was a sense of my journey as a pioneer consumer activist committed to doing something about changing our community's and service systems' responses to women dismissed and excluded from services or subjected to institutionalised punishment regimes because of our failure to conform both to society's expectation of what it means to be a woman (Grey: 2006, Emerson: 2006) and to what psychiatry dictates it means to be 'mentally ill'.

### **DISCRIMINATION AND THE 'BORDERLINE' LABEL**

Grey is fascinated that so few people have heard of 'borderline' even though the population incidence is similar to or greater than many of the psychotic experiences. This is a fascination that I share. Often when I am speaking to generic groups of consumers and/or carers they express if not total ignorance about the existence of the label of 'borderline' then certainly enormous vagary about it. An astounding propensity to judge and blame women with this label seems to have seeped into some people's judgements through experiences or altercations which they haven't understood, the attitudes of professionals, and/or the misleading information being promulgated by organisations involved in the public perception of mental illness. Perhaps this reflects the lack of precision in the industry's understanding of 'borderline' as well as territorial wars about its place in psychiatry at all. However, I am convinced that it also reflects the gendered and

social class<sup>12</sup> implications of this diagnosis and the failure of the mental health lobby to significantly educate the public about the genuine nature of the distress of women diagnosed in this way.

In previous presentations<sup>13</sup> I have spoken about the failure of organisations, which profess to educate the public, carers, and mad folk about so-called mental illness. I have been particularly critical of SANE and the Mental Health Council of Australia (MHCA). My analysis of the material produced by these organisations causes me to worry because it is so driven by the medico-scientific agenda, which frequently trivialises the impact of the social and relational both in understanding the seriousness of the experiences that get labelled as ‘borderline’ and in understanding the aetiology of this distress. The materials produced about mental illness by these organisations and their public utterances too often reflect the dominant story of brain disease which suits many including most psychiatrists<sup>14</sup>, many psychologists, the health industry, most carer lobby groups, drug companies, of course, and some consumers whose own personal stories resonate.

It is difficult for both SANE and the MHCA to move from a base of such assumptions to democratic inclusion of the ‘borderline’ experience. It doesn’t fit very comfortably within such a medical model. After significant lobbying (on my part and I assume others’ as well) we have had very tokenistic wins. ‘Borderline’ is no longer absent from SANE’s worldview but it is poorly represented and certainly not prioritised. I have written previously about some forces at play here and they include the increasing power, and reluctance, of the organised ‘carer’ lobby to sufficiently embrace the idea that some people with adult mental health problems have experienced abuse, neglect and trauma as children and that these statistics rise significantly when we look at women who have been labelled as having ‘borderline’. (Shaw & Proctor, 2004)<sup>15</sup>.

Survivor/user/consumer movements can also discriminate against people labelled as having ‘borderline’. Kalikhat (2004), a Black woman in the United Kingdom who has a diagnosis of ‘borderline’, reflects on the discrimination she experiences because she is a woman, because she is Black, because she has a psychiatric diagnosis, and because she has a specific diagnosis of personality disorder. In the table below she charts her experience of discrimination.

A personal view of the degree of discrimination and oppression in various situations as a result of being Black, a woman, someone with a psychiatric diagnosis and someone with a specific diagnosis of personality disorder.

	Society	My community	mh user (consumer) movement	mh services
being Black	**	-	**	**
being female	*	*	-	*
having a psychiatric diagnosis	***	***	-	*
having a specific diagnosis of personality disorder	*	*	***	***
* = degree of oppression				

In describing her experiences she writes:

*This considering of degrees of discrimination and oppression fascinates me. From the chart above ... society discriminates against me for having a psychiatric diagnosis and obviously for being Black. Similarly, my own community discriminates against me for having a psychiatric diagnosis but obviously not for being Black. Both discriminate against me (but to a much lesser extent) for being a woman and for having a specific diagnosis of personality disorder. In comparison, the MH service user [consumer] movement (that very right-on body that campaigns for users’ [consumers’] rights) obviously does not discriminate against those with a psychiatric diagnosis but can be very discriminatory against those known to have a specific diagnosis of personality disorder and are Black. Statutory MH services (who are meant to have an understanding of MH issues and work in an anti-discriminatory way) similarly discriminate against those with a diagnosis of personality disorder (typically referring to us as ‘heartsick’ patients) and those who are Black, and also against women and those with a psychiatric diagnosis (these last being the very people they are meant to be helping). (2004:27)*

In a psychiatric text that Anne Olsen and I contributed to a few years ago we searched for words to describe the experience of discrimination endured by many patients with personality disorder labels within mental health services and we realised that despite all the attention that had been drawn to issues of discrimination in society there was still a dearth of material on discrimination within mental health services themselves. After talking to many people we concluded that:

*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.'* (Olsen & Epstein: 2001:17)

I am sometimes reluctant to suggest that people labelled with 'borderline' search the literature to educate themselves about what the label means. This is not because I believe they have deficiencies in perception or interpretation of the material but rather because I have found that some of the available mainstream texts and journal articles use disrespectful language that reflects judgmental and pious attitudes. My experience is that this language has the potential to do harm. Grey (2006) writes:

*The literature on BPD very strongly gives the impression that BPD is predominantly a 'problem' for the psychiatric profession, rather than for the people who are given that diagnosis. Reference to 'management' of these patients and complaints about their 'manipulation' are commonplace and frame the problem in terms of feelings of the therapist. (Cawels 1992:30-31)*

One of the tests of respectful presentation about issues to do with so called mental illness is that people labelled as mentally ill can sit in the audience and bear to hear, even feel uplifted sometimes, when their experiences are reflected in the story that is being told. Similarly I believe that one of the signifiers of outstanding research, literature and language is that people labelled with 'borderline' can read it, feel informed, and not feel 'othered',<sup>16</sup> insulted or belittled. This does not mean that it should be untruthful. Bullshit niceness about us is also tedious and part of the persona of many of my friends who carry this label is a canny antenna for insincerity. The answer, of course, is that nobody should be talking about us without us.<sup>17</sup> Unfortunately, this has, in my experience, rarely been the case.

In the papers previously mentioned I have had an opportunity to examine the policy coming from the Mental Health Branch through progressive National Mental Health Strategies and plans<sup>18</sup>. Not surprisingly 'borderline' is almost totally invisible. This angers me for two reasons. Firstly, this invisibility in public policy provides easy political justification for services to kick us out or not let us in even when we are desperate. This, of course, disproportionately affects those who are already marginalised. Desperate for entrée, we are seen to put unreasonable demands on the inadequate services that do exist, encouraging further bureaucratic rationalisation using language that denies the seriousness of our distress. Secondly, it replicates the same invisibility we often experienced in our cultural and relational milieu as children and adolescents.

I have also been a keen observer of the ways public policy is translated into practice at a local level. I have collected and explored information being disseminated by local area mental health services, mainly in Victoria<sup>19</sup>, informally analysing the messages that are systemically being given to women who have been diagnosed with 'borderline' and their friends and supporters. In a study of the material and brochures produced by 15 public mental health services in Victoria in 2002 all listed their client groups in descending order from Schizophrenia 'down to' Severe or Borderline Personality Disorder. In 100% of the cases I collected 'borderline' was the last group considered for 'care'<sup>20</sup>. Most of the brochures added a provision that people diagnosed with 'borderline' would also have to be at risk of harming self or others. This is distressing. Firstly it is distressing because it gives women labelled with 'borderline' a very strong and familiar message that **they** are unimportant. Secondly it is distressing because it gives women a very compelling message that services will only be forthcoming for those of them who least want to be there or who are most able to escalate their symptoms to the point where they are at risk to themselves or others (for which, by the way, they know they will generally be punished).

In Victoria this is mitigated to some extent by the establishment of *Spectrum: the personality disorder service of Victoria* which has a clinical program as well as statewide community services and treatment services teams. Two consumers with a label of 'borderline' have told me that Spectrum has, quite literally, saved their lives. Doubtless others will differ but in Victoria there is, at least, something. A major problem is that before Spectrum services can be offered people are required to already have a case manager in the very same community mental health service system that doesn't prioritise them. I am aware of the practicalities of this from a clinical perspective but from a consumer perspective it is often seen as a self-defeating policy. It is frustrating for many.<sup>21</sup>

Interestingly, this language of service delivery and policy priority is a very fickle thing. It is in constant change as critics like me chase it. I have learned over 16 years that the language of 'seriousness', for example, has an indomitable capacity to morph under duress.<sup>22</sup> The perverse nature of this information should be a serious worry to all of us. Felicity Grey ponders the exclusion of 'borderline' from institutional definitions of seriousness when she notes:

*It [borderline] is an extremely serious condition. It has a comparable suicide rate to both schizophrenia and bipolar disorder, estimated at 9%, and a higher prevalence in the Australian community than either, affecting 2% of adults – a total of about 300,000 Australians. And yet it has a significantly lower profile in the Australian community than these figures would suggest it warrants. (2006:2)*

Assumptions about who we are as women labelled as having 'borderline' within public mental health services comes, in large part at least, from these exclusionary practices and policies. In Victoria, services consistently refuse any service to most women with a 'borderline' label as a primary diagnosis who seek access. This creates, obviously to me but seemingly not so obviously to people working in the system, a distortion of the image of what it means to have a diagnosis of 'borderline'. Clinicians in public services are constantly exposed to what they tell me are the '*never-ending demands of extraordinarily difficult 'BPDs'*'. Those of us who hold the diagnosis, -- often as part of a 'portfolio of disorders' -- but do not have the level of disability or complexity, quickly get told we are not a service priority and we simply have no choice but to try and find something else, often falling through rapidly widening and dangerous cracks in private/public, medical/community service provision.<sup>23</sup>

But if you are a clinician under these social conditions you don't get to see those of us who are refused services in the public mental health domain. You don't get to know us, talk with us and reassess your judgment about what 'borderline' means. The political process of exclusion actually creates all sorts of distortions in clinicians' perceptions including the two major ones. Firstly, women diagnosed with 'borderline' use a disproportionate amount of service time and service resource. This is myth. If public mental health services were servicing only the same very elite level of severity and disability for people with a diagnosis of schizophrenia, for example, they would be saying exactly the same things about them, perhaps depending on their gender. The second myth is that if clinicians are nice to 'borderlines' they'll be manipulated and the service will be inundated. (Epstein 2005).

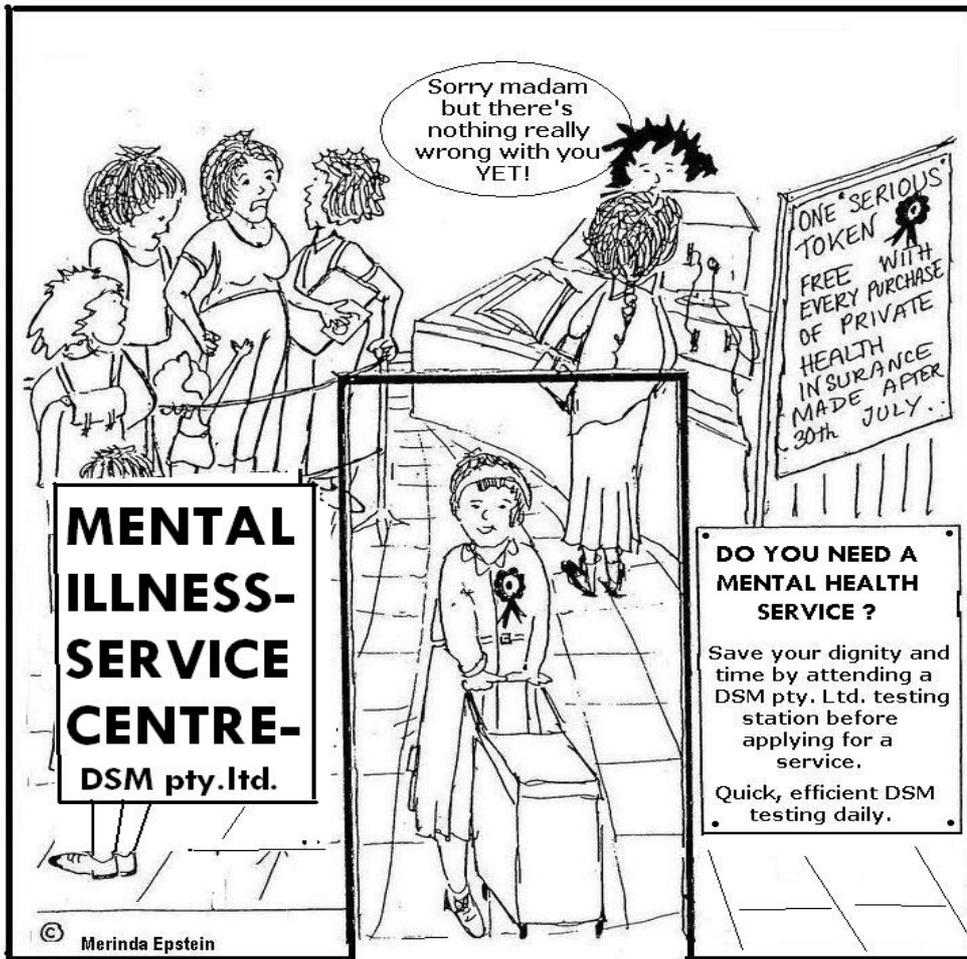
#### **A SMIDGIN OF CLINICAL INFORMATION (FROM A CONSUMER PERSPECTIVE)**

Grey (2006) comments that Borderline Personality Disorder has an uneasy place within the mental health field. She draws our attention to the work of Cauwels (1992) who suggests that:

*the 'entirety [of the borderline experience] can be summarized in a single word: difficulty.' She [Cauwels] titles her book about borderline "Imbroglia", which brings together ideas of a confused mess, an acutely painful or embarrassing misunderstanding and a violently confused or bitterly complicated altercation.*

Like all psychiatric labels, Borderline Personality Disorder depends upon the practice of diagnosis. The practice is fundamental to psychiatry, and other mental health systems, and is based on the assumption that mental illnesses are diseases like physical illnesses. Diagnosing is also based on the idea that these 'diseases' can be identified and categorised as such by the mental health professional: the emphasis is on discovering physical causes and then finding 'appropriate' medication. (Shaw & Proctor, 2004)

I know that the vast majority of people in this room will be familiar with the fourth edition of the Diagnostic and Statistical Manual or what is usually just known as the DSM. (DSM: 1994) Nonetheless, it is essential that everyone here be empowered with the knowledge that this is a very influential document. The DSM is a classification system used in psychiatry to help clinicians make diagnoses. It is particularly problematic for people with so-called personality disorders because the DSM IV divides people's pain and mental distress into multiple categories or axes of which I will mention two. The first one is reserved for what the authors regard as the 'real' psychiatric illnesses because they are seen to have a physical aetiology. These are the ones that some people within the consumer movement jokingly call the 'Capital I' illnesses' – Schizophrenia, Bi-polar and so on. By virtue of their hierarchical (or what a friend of mine very amusingly called 'lowrarchical'<sup>24</sup>) position within this document these labels are seen as 'serious' by default.<sup>25</sup> On the other hand, personality disorders sit with intellectual disability in a section that describes AXIS II diagnoses. These are not seen to be 'proper mental illnesses'. They are instead described as disorders and, as such, they are rarely seen to be deserving of resource priority. Viewed from the perspective of distress legitimacy, service inclusion, and resource distribution this volume can be seen as a major source of discrimination against all people with personality disorder diagnoses particularly where this is their primary diagnosis.<sup>26</sup>



In my opinion Axis II diagnoses will continue to be the poor cousins while we still think of mental health in terms of mental illness and allow the 'medical model' and documents such as the DSM to rule so much of our thinking. The somewhat curious relationship between the American Psychiatric Society, which produces the DSM, and the American health insurance industry also influences the DSM profiles because it is in the political and economic interest of the health insurance companies to make sure that Axis II diagnoses remain there. Although they may well argue to the contrary, this is, in part at least, due to the influence of multinational drug companies and the fact that, thus far, treatments for Axis II diagnoses are not primarily reliant on medical drug interventions and are therefore of little economic interest.

### GETTING 'THAT' DIAGNOSIS

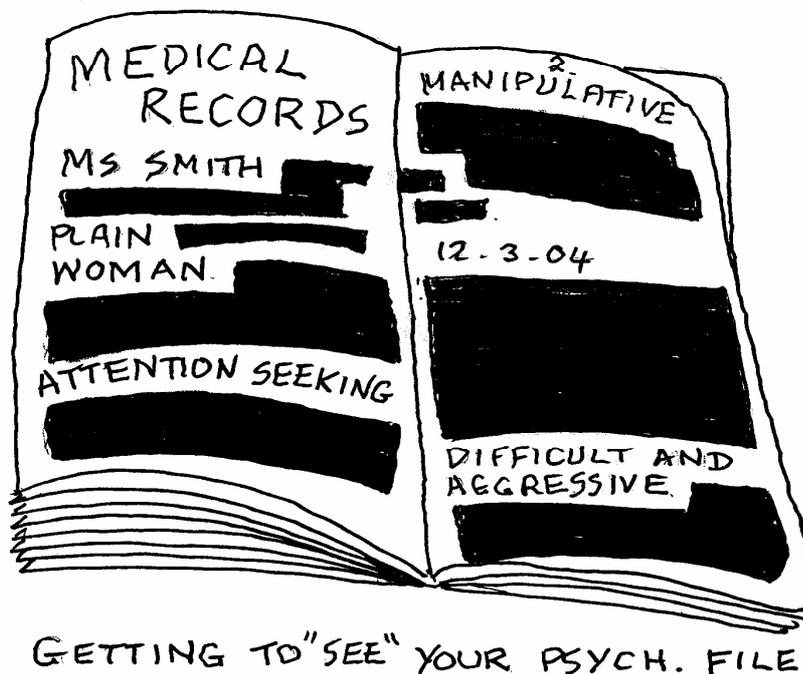
The criteria used to diagnose 'borderline' in the DSM include (and I quote using the alienating language of the document) the presence of intense bouts of anger, anxiety or depression lasting only a few hours; chronic feelings of emptiness; impulsive and self-destructive acts; suicidal behaviours; transient, stress-related dissociation; and a sense of self that is fragile or contradictory.

There are so many problematic issues for consumers about having our personalities pathologised but I want to leave this here for the moment and return to it. There are immediate issues in relation to diagnosis that are troubling. One consumer described the process of being diagnosed with 'borderline' like this:

*'they tried every other diagnosis they could think of and when I didn't fit anywhere they squished me into a borderline diagnosis. I didn't fit properly and it hurt.'* (Epstein, 1998:5)

My own experience is similar. I can no longer accept that psychiatry is anywhere near a precise science. I have had many diagnoses over my 'career' through psychiatric services. Diagnoses change for sometimes extremely spurious

reasons and, on another level, although they are nothing but social constructs, they can be reified into absolutes that then dictate every interpersonal interaction you are able to construct from that time on. This intrudes to inform important relationships not only with people working in mental health but also in physical health, non-government and other agencies and services. Medical records aid and abet this insidious process. One of the most therapeutically useful things I have ever done was to vigorously pursue my health records under Freedom of Information legislation. It was so good to see evidence to support my belief that I was being vilified with inflammatory, inaccurate, and at times perniciously judgmental assessments of my integrity.



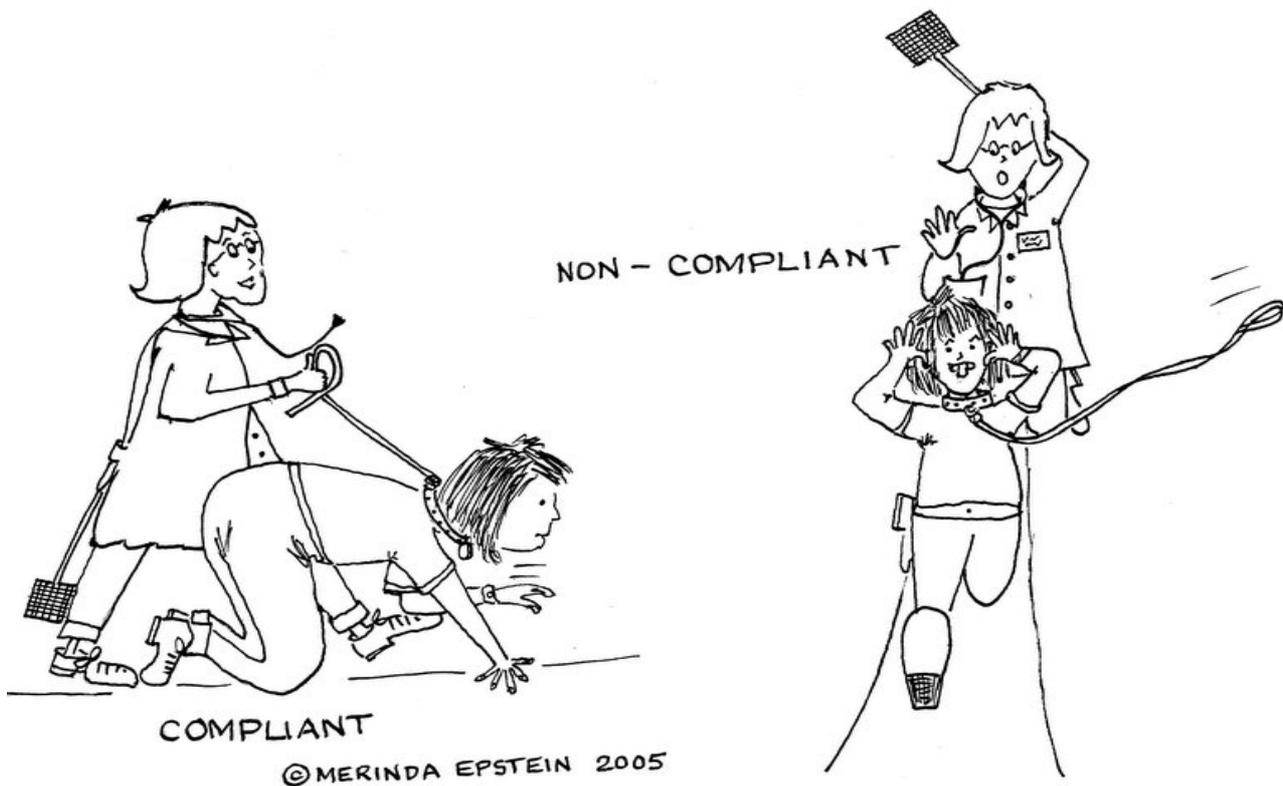
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The fact that this was happening behind my back is, in my opinion, a disgrace--although I knew that this horrible stuff was there because it was reflected in the practice that I had too often to tolerate. Any assumptions by clinicians that we don't have a pretty reasonable grasp of what is being written about us are naïve. However, I had not anticipated the degree to which what was being written and the language that was being used would correlate with changes in diagnosis. For me the best thing about getting to see my health records was that they dispelled lingering fears I harboured that my mistrust of their content might have been burgeoning paranoia.

One of the reasons that I eventually decided to 'come clean' publicly about my experience of being diagnosed with 'borderline' was that my encounter with treatment, vindicated by my records, deteriorated so noticeably once this diagnosis started to appear in my file. I hated it and wanted desperately to wash my file clean. I was angered by the language, distressed by the assumptions, and infuriated by the almost instantaneous dismissive attitudes this diagnosis wrought for me in public sector psychiatry. This is not everyone's experience however. Some women are relieved to get a diagnosis, any diagnosis at all. They tell me it is about identity and acceptance 'within the system'. It goes a little way

towards shifting the blame some carry. Others are relieved to get a 'borderline' diagnosis because the diagnostic characteristics resonate for them and with their lives.

The other thing that was so obvious in my case was that I was only given a diagnosis of 'borderline' when I started to stand up for myself as a person and as a woman. It became apparent to me, much later, that my latent attempts to empower myself in the world, inelegant at first because these skills were stunted by early life experiences, were consistently being demonised once I got this diagnosis. My only escape was to give up and allow myself to become institutionalised. For example, two independent 'therapists'<sup>27</sup> totally missed my quite blatant symptoms of dreadful sadness, self-loathing and chronic defeat (clinical depression) and encouraged what they saw as my 'growing self-knowledge' (insight?) which was obvious to them by my acceptance at last that I **was** a *'bad-dependent-histrionic-demanding woman' who didn't have a 'real' mental illness!* This was very destructive as I took the bait easily. Many consumers say that they were diagnosed with 'borderline' as a punishment. Some clinicians are also very critical of their colleagues for the way the diagnosis is used, claiming that every woman who self harms or is angry ends up being given a 'borderline' diagnosis, or, at least, is erroneously described as having 'borderline' traits. This is particularly so for women if they are working class cut or burn and are 'non-compliant' or resistant. Women's empowerment systemically gets named 'borderline' even for women who also have a primary Axis 1 diagnosis. At the same time 'empowerment' is being misrepresented as something that most 'mental health patients' don't have enough of and which can somehow be conferred on them by clinicians and others working in the field. There seems to be an unhealthy contradiction in this logic.



There are enormous repercussions here for women. Some emanate, I think, from the nature of psychiatry and clinical psychology and some from the nature of society and the load society confers on these two institutions to find medical fixes to very difficult, long term and costly social problems. For example, if a diagnosis of 'borderline' is whacked onto many women who are not conforming to contemporary images of femininity – stereotypes of the 'good' woman (Matthews, 1984; Emerson 2005) or to the unwritten script of psychiatry that 'real' illnesses are legitimate – just like any other illness, the consequence is that women who are angry, distressed and desperate for help but are not seen to have 'real' illnesses will remain ineligible for this social exculpation. We will remain 'bad' or, at least, 'difficult', women in the eyes of many clinicians, the sector and society (Smith: 2006). If woman who are 'difficult' are routinely given the label of 'borderline' regardless of any other factors then the label becomes synonymous with 'difficult woman' in the worldview of the sector and in the minds of individual clinicians. Hence a serious Catch 22 situation is

created. This, in turn, reinforces the culture of fear in relation to the diagnoses with an expectation of 'bad woman' and potential, if not real, abuse of women who are labelled in this way.

As with much discrimination the challenge is that there is an element of truth. Many of us can be really 'in-your-face' and, I guess, *difficult*. In my opinion we have every right to be given our lives but that, perhaps, is another story. The origin of this discrimination is the same as, for example, discrimination against men with psychotic illness in relation to violence. There is an element of truth but then this grows into totally unacceptable and dangerous exaggeration and community reinforced generalisations created to set society's mind at rest -- an insidious process obfuscated by a refusal to accurately name discrimination and oppression for what they are. Stigma may be the mark of infamy but discrimination is comprised of the actions of others who violently sanction those who carry the stigmata. The idea of self-stigmatisation (Rüsch:2006) is, in my opinion, the ultimate de-politicalisation of the 'borderline' experience, and insulting. However, if we accept the idea that discrimination is socially constructed and applies, for example, both to the automatic assumption of 'badness' in women who have been diagnosed with 'borderline' and 'dangerousness' in men who have been diagnosed with schizophrenia then why do we hear so much about discrimination against one group and almost nothing about discrimination against the other?

Grey (2006) argues that, while the official DSM description of 'borderline' might be seen as bad enough, unofficial diagnostic methods are sometimes even more worrying. These include the therapist having a strong, negative response to the individual. Grey draws on the following striking example:

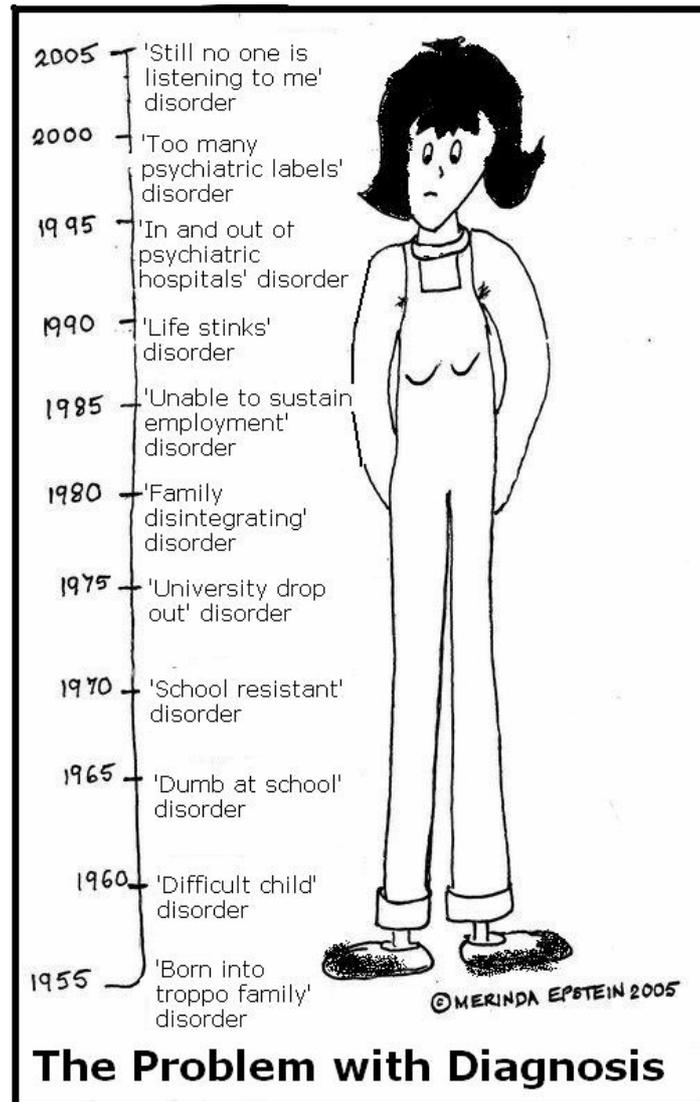
*At one outpatient clinic, the category 'borderline' was taught through the 'meat-grinder' sensation: the chief resident explained to the others that if you were talking to a patient and felt as if your internal organs were turning into hamburger meat (you felt scared; you felt manipulated by someone unpredictable; still, you liked her), that patient most likely had a borderline personality disorder. (Kerr, in Grey 2004:4)*

Judith Herman, an American, feminist psychiatrist, dislikes the label and the damaging consequences of classifying a whole group of women with abuse, trauma and neglect histories, so negatively. From looking at the mental health profession's response to people diagnosed with 'borderline' she has concluded that it amounts to "a sophisticated term of patient abuse". (Herman, in *Mental Health Commission of New Zealand: 2004*).<sup>28</sup> Grey argues that the label 'Borderline Personality Disorder' is an historical relic which often mystifies consumers and their supporters and which is more pejorative than helpful. (2006:13). She cites Becker's analysis. In reference to the diagnosis of Borderline Personality Disorder, Becker concludes that:

*The distress is real: the diagnosis is fiction. (2007:48)*

## **PATHOLOGISING PERSONALITIES**

It seems to me that as people interested in mental **health** service delivery we have lost sight of the fact that mental illness is different from mental health -- except, of course, when we are talking in broad terms about population health and well being, but this isn't what I mean. In the search for ways to explain or describe 'seriousness' we have created categories of 'illness' to which those of us wanting services must aspire. When you think about it this is a crazy situation as well as a crazy making one. It is an imperative part of my thinking in this area but I experience it also as a conundrum.



Recently, Mona Ruijs, a young filmmaker who is making a film about psychiatry approached me.<sup>29</sup> She asked me to have a look at the script and speak to her about it. It is a quirky, funny take on psychiatry's apparent thirst for new diagnoses to impose on people. This is a bit of a familiar critique and it is certainly a common theme from sociology – my academic discipline. I share disquiet about what seems to be increased psychiatric activity, and especially psychological activity, in the realm of personality. As the script suggests soon we will be calling jet lag, CIRCADIAN RHYTHM SLEEP DISORDER and describing people who are quiet as having SELECTIVE MUTISM DISORDER.

Sociologists also have a critical tradition based in academe rather than the theatre. Grey (2006) points out that some commentators have described 'borderline' not as an individual pathology but as a consequence of a particular social context. For example, Edward Shorter dismisses 'borderline' as a:

*'Woody Allen syndrome' generated by very specific East-Coast American cultural pathology; 'not recognised in Iowa City or Mobile, certainly not in Tangiers or Bucharest'. (2006:4)*

Millon (2004) points out that contemporary cultural life, especially in an American context, is perverse, chaotic, and frayed. He argues that the symptomatology of 'borderline' imitates this:

*Our amorphous cultural state is mirrored in the interpersonal vacillations and affective instabilities that typify the longitudinal affective distress seen in patients presenting with what is called a borderline personality. (in Grey 2006:4)*

Others argue that it has become a fashionable diagnosis. Becker concurs:

*Just as the hysterical neurotic of Freud's time - plagued by conflicts of conscience and desire - exemplified the repressive Western culture at the turn of the century, so certain disturbances in an individual's sense of identity and difficulties in maintaining stable human relationships - characteristics attributed to the borderline personality - may reflect the fragmentation of contemporary society' (Wirth-Cauchon: 2001:12)*

Ron Coleman<sup>30</sup> humorously picked up the same theme, naming the ridiculous extremes that can be reached when we start pathologising the very act of being human in contemporary society. Yes! I too laughed at these exaggerations and the point Coleman and Ruijs were trying to make but it was only with 'one hand clapping'.

My inability to fully appreciate the joke comes from my uneasiness about the shady line drawn between laughing at the silliness of pathologising and labelling absolutely everything and interfering in people's lives in these kinds of ways and the implied judgments about the silliness of people who might be 'conned' into believing propaganda<sup>31</sup> about the need for such professional interventions in their lives.

I think there are some critical assumptions informing the fact that we laugh. These include assumptions about social class combined with many Australians' underlying distrust of the Americanisation of our culture. I don't fully understand this but I suspect it might come from the American media where there is a persistent portrayal of wealthy people seeking psychoanalysis for what appear to be very trivial and self-centred concerns. There is an assumption here that these people don't have 'proper mental illness' but, rather, there is 'just' something wrong with their personalities (even if this is demonstrated 'only' by the fact that they continue to spend huge amounts of money trying to buy happiness!) Yes. This is funny and I laughed too, but there is a dangerous conjecture informing this portrayal of people who are often dismissed as 'the worried well': that is, that people with so-called personality disorders are invariably wealthy, or at least have means and no 'real' needs, while people with 'serious' and 'real' mental illness are, by definition, living in poverty and have quite obvious 'real' needs.

The literature on 'borderline' significantly contradicts this. The majority of women who are labelled with this diagnosis both come from the poorest backgrounds and live on the margins with few or no financial resources. The lack of meaningful analysis of gender, class and ethnicity around these issues is paramount.

Maybe the label of 'borderline' is, after all, appropriate. Women with 'borderline' are on the margins (conceptually and quite literally on the border line) when it comes to access not only to mental health services when they know they need them but also to other supports for people with disabilities, child support and respite services, even disability pensions. Most of these services need proof of pathology or proof of registration in a mental health service or proof of an ongoing engagement with a psychiatrist/therapist and for many women diagnosed with 'borderline' these requirements are not only often made difficult to satisfy by dubious policy directions but are also both financially and symptomatically impossible.

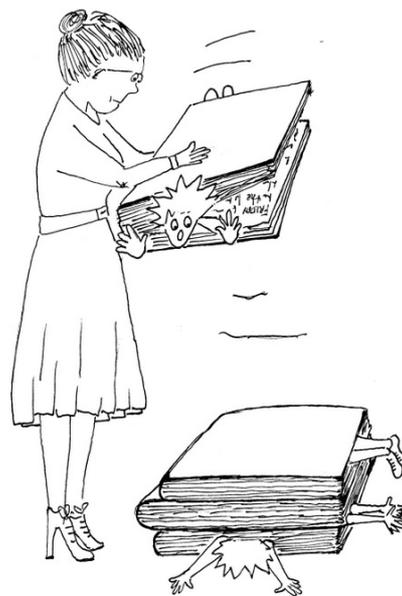
### **THE SOCIAL CONSTRUCTION OF BORDERLINE PERSONALITY DISORDER**

I am interested in the contribution the disciplines of sociology and anthropology can offer to the field of psychiatry. For many decades sociologists have been writing about stigma – Goffman (1963) coining the term -- and about psychiatry as an institution of social control. Sociologists and historians have been interested in de-institutionalisation and the construction and growth to political eminence of the brain disease interpretation of madness. With the rapid medicalisation of psychiatry during the 20th century a strange demarcation has appeared between those forms of madness that can be seen as physiological and those that continue to be seen as defects of personality. Of course, sociologists are unsurprised by the language manipulation that is needed to move from the inclusivity of 'madness' to the creation of an illness industry and demarcation disputes between the different clinical groups for ascendancy in this industry.

Much that happens in psychiatry, including much 'psychotherapy', can work to individualise and de-politicise people. The exceptions are perhaps some of the feminist therapies and other therapies that are politically informed. Many

consumers have a particular problem with the emphasis on ‘behaviour’ that is the contemporary orientation of much of the therapy that is aimed at people labelled as having ‘borderline’. At a recent conference I attended<sup>32</sup> consumers were jokingly referring to Dialectical Behaviour Therapy as Diabolical Behaviour Therapy. Unfortunately the term ‘behaviour’ has become a dirty word for many consumers in psychiatry. It is yet another term of derision that is too often prefixed by the word ‘just’ to describe women labelled as having ‘borderline’ (ie. ‘It’s ‘just behavioural’). The absence of the political, either inadvertently or deliberately, places all the responsibility back on to the person as an individual without any sense of community responsibility or any sense of personal power to instigate or contribute towards social change. Consumers have named this as potentially damaging, especially when adult angst and distress have such obvious roots in social situations that need political remedies. In failing, confidently and publicly, to name child abuse and neglect, male sexual violence, the disenfranchisement of indigenous communities and removal of their children (for example) as unquestionable antecedents of so much adult psychological distress, anger and disability, psychiatry and its allies are seen by many consumers as complicit. Emerson develops this argument further using her own experience of Dialectical Behaviour Therapy:

*My own experience of DBT informs my question: after attempting to organise a consciousness raising group to discuss the causative role of sexual violence and distributing fliers that proudly defamed Charcot, Breuer and Freud et. al., I was told, ‘we are not political here...’ My actions were deemed ‘therapy interfering behaviours’ which, at least, seemed to lead to a comprehensive and personalised discharge plan... ” (2006:3)*



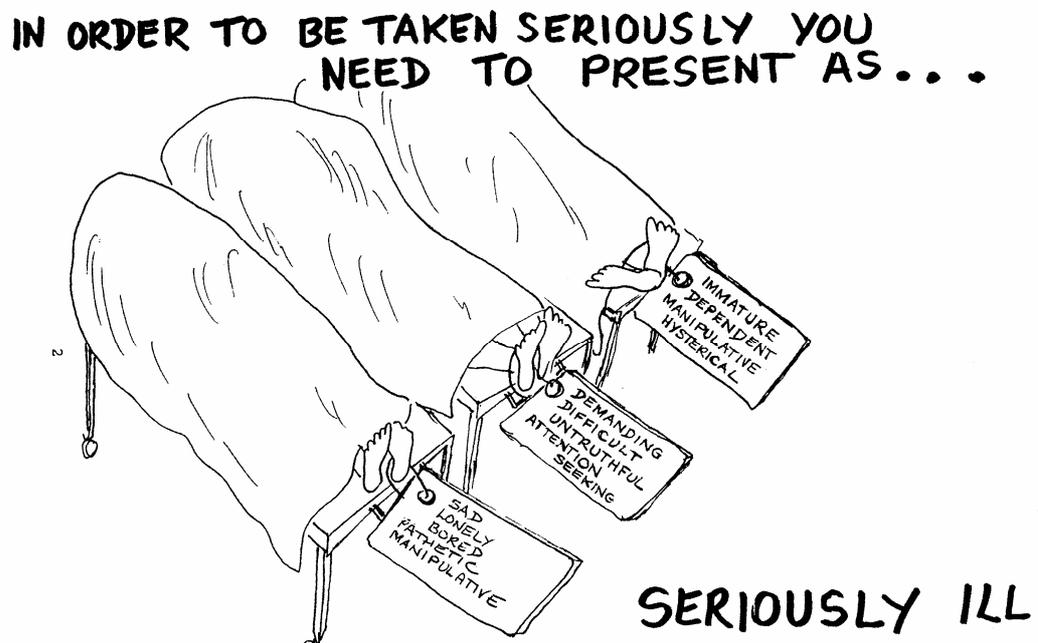
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©MERINDA EPSTEIN 2005

In becoming politically active and channelling my anger through my political participation, not just in relation to the mad folks agenda but also in demanding change in the areas of political life that so damage many women labelled with ‘borderline’, I have progressed towards my own mental healing. Politics, in the form of demanding social change, is important to me. Having said this, however, I have also sought, been refused and eventually located ‘therapy’ from psychiatrists, clinical psychologists and counsellors, traditional medicine and alternative practitioners with mixed success – some has been damaging. I am now both a very active and often radical political campaigner for systemic change to the culture and practices of both psychiatry and clinical psychology **and** someone still trying to put my own life in order with the help of everything that I can muster – including a pretty damn good psychiatrist who tolerates my public utterances about her with suitable aplomb most of the time. A sometimes-depleted rhetoric from the social sciences --or indeed from a vanguard consumer movement --that inadequately understands some people’s desperate search for credibility and visibility within the mental health service sector can be as patriarchal as the institutions they critique. To assume ‘the other’ is inherently misinformed misjudges the personal agency of ‘the other’ wherever they sit in the debate. Disciplines and movements that offer critique are absolutely vital but if they offer nothing but critique and

few alternatives, and in so doing make implicit and sometimes explicit judgments about the political gullibility of those of us whose lived experience differs from theirs, then what they are offering is, perhaps, inadequately inclusive.

### PERVERSE INCENTIVES AND INVISIBILITY

The rise and rise of psychiatry and exponential increase in pathologising personalities by psychologists and psychiatrists is potentially dangerous to people who are distressed, and likely to be extremely expensive and wasteful of precious community resources. We do not need more and more personalities defined as disordered and, yes, of necessity there are political, social and cultural determinants of all so-called 'mental illnesses' and, perhaps, particularly 'personality disorders'. At the same time many women can and are seriously disabled by the experiences that collectively get labelled 'borderline'. They are trying desperately to get assistance from a system that is no longer set up to provide for them. This has the not unexpected consequence of women learning that they have to escalate their rage in order to attract any attention at all. I use the words 'attracting attention' intentionally here because without attention many women perish.



The dismissive term 'attention seeking' corrupts the urgency and integrity of the endeavour. Must people have an illness defined in the DSM for the seriousness of their distress to be apparent? Why? I cannot see any logical reason why this document should stand as a sentry denying the urgent need on the basis of semantics. The way it works at the moment is to create false incentives to get, or at least be seen to get, 'sick' in order to receive help to find 'wellness' but it also creates anomalies that consistently throw me back into feeling that I am that little boy who is the only one who can see that the Emperor has no clothes.<sup>33</sup>

Over the last fifteen years of my journey through the bewildering world of mental health politics I have sometimes felt incredibly alone. This aloneness and the sense, nearly all the time, that what seemed so profoundly obvious to me was invisible to so many others with whom I was coming into contact was frustrating and sometimes mortifying because I felt disempowered to make things change for the many women whose stories had been mortgaged to me. It was often as though I was speaking another language and I was punished for speaking up with implications that I had diminished mental capacity to 'understand what was really important'.

## OPPRESSION AND HIERARCHIES OF SHAME

I was dismayed that this critique of my actions in trying to raise the agenda for women labelled with 'borderline' was sometimes coming from consumers themselves and this is one of the reasons I wanted to talk today. I am now convinced that the experience of being locked out of the system, being refused 'illness' status, and having overtly serious and disabling experiences defined institutionally as non-serious is a different form of oppression from being 'locked in', 'locked up' and cast off as unredeemable and unrecoverably disabled. I am not advocating a hierarchy of oppression. Far from it, I am attempting to understand different forms of oppression and the complexity of our fight and responsibility as consumer activists. At a recent conference Nicole Emerson put it better than I have been able to do

*On Tuesday afternoon I had the opportunity to momentarily gaze at the tattoo - "Psychotic and Proud" - of our keynote speaker, Ron Coleman. At first this prompted me to wonder whether the day will come when women with the so-called borderline personality disorder are able to display the marks of 'self harm' (their memorial to sexual violence perhaps) with such unfettered pride. But this hyperbole, this 'disavowed rage' perhaps, also reminded me of the unhelpful (if intriguing) battle between competing oppressions: illness versus disorder, addiction versus mental illness ... which, in the end, works to construct a hierarchy of shame that replicates the very psychiatric practice we should be critiquing. (Emerson, 2006:3)*

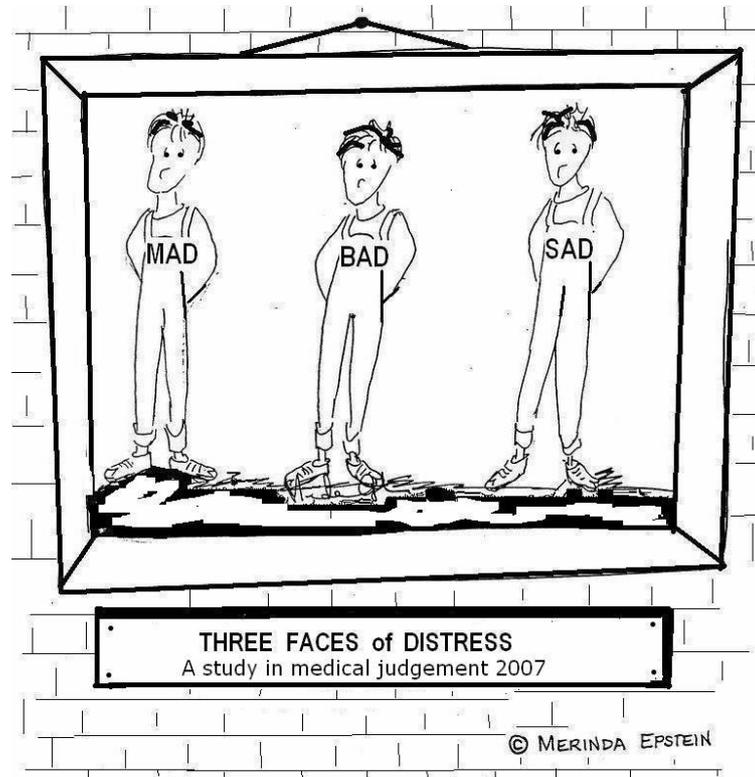
I am fascinated by this idea of a hierarchy of shame which I think is thriving in mental health politics in Australia at this time, encouraged by anti-stigma campaigns which emphasise the 'real illness' understanding of mental distress. It disadvantages and sometimes devastates those among us who might not have a real physiological mental illness on which to hang our experiences of paralysing psychological distress, social failure, stunted careers, academic defeats and often economic dependency. In western democratic societies there are very few life circumstances that can 'protect' you, in part at least, from the devastating cultural consequences of these failures. Chronic, disabling, physical illness and overt disability might be two of those few characteristics that can help you get the monkey of disgrace off your back and out of your psyche. Of course, those who promote the 'just like any other illness' paradigm of discrimination limitation would no doubt claim that people with mental illness suffer from stigma precisely because mental illness is not seen by society as just like other serious illnesses and hence the necessity to inform the public. My plea would be for those people, particularly those who represent influential organisations, to try and put themselves in the shoes of women whose distress has been, up until recently, demonstrably not physical illness. What do these messages say to these women about their personal worth?

Felicity Grey was telling me about a term that is now being used in her field of linguistics. As much as jargon annoys me I was intrigued by this term because it precisely describes a concept I have been grappling with. The word is 'stigmaphobia' and it describes the situation that exists when one stigmatised group tries to get themselves off the bottom of the pile by dumping on another group or when one political interest group representing disenfranchised people uses language and metaphors which discriminate against another oppressed group.

It applies in many ways in mental health. For example a young woman in Melbourne has self-published a book which she has called, *Living with non drug induced psychosis*. Here she is distancing her own experiences from those of drug users with 'mental illnesses'. In much the same way there seems to be a funny sort of attempt by consumers and others to want to cleanse mental illness. Perhaps this is for really understandable reasons -- but those who are seen to behave in ways that disgrace the new found quasi-respectability of mental illness are a challenge to the image makers and can become disposable especially when they don't even have a 'real' mental illness to give them credibility. In a previous keynote at THEMHS (1996) I identified this issue as a major one and gave examples of how it works not just against people diagnosed with so-called personality disorders but, indeed, to divide and conquer right across the spectrum of illness, distress and disability experiences.

The psych. survivor (consumer) movement is the other best way to shake off the mantle of disgrace. As a movement of social resistance to society's vilification of madness it is a public representation of our pride in who we are in the world. In the tradition of the feminist movement, the gay pride movement and other social change movements it has powerful potential. Throwing away the cloak of shame is liberating but not if we do so by cleansing our image in a way that is damaging to some of our members. Liberation requires us to responsibly critique damaging assumptions and social hierarchies within our own organisations. It also requires us to be inclusive and refuse to bow to the language of psychiatry which is hierarchical and patriarchal, and, instead, claim a language of pride that must never differentiate between different forms of madness or, indeed, fail to appreciate that many women with a 'borderline' label are scolded by the institutions of psychiatry precisely because they are **not** seen to qualify as 'mad'. The semantic antics of the

DSM classification systems are powerful and damaging for many and can lead to implicit social exclusion even from our own organisations. The language of mad pride must not be assumed to be inclusive. Women denied the status of madness within the mental illness system might need to be explicitly invited to join with us before they feel they belong. Our movement can and must have a shared sense of purpose and humour.



As Persimmon Blackbridge, a Canadian consumer-writer, put so well for us in her book, *Prozac Highway* (Blackbridge, 1997:32)

*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.*

#### **'BORDERLINE' AND CHILDHOOD TRAUMA**

After reading first hand accounts and speaking to many women who have been diagnosed with 'borderline' it is obvious that many saw freedom in proclaiming histories of child abuse, neglect and trauma. As painful as these experiences were for many, naming themselves in a political act as a survivor, and for many as a BORDERLINE, was the most powerful way that they knew to deal with the discrimination that they were facing on a daily basis.

We know that 'borderline' is a 'disorder' that disproportionately affects women, primarily young women (Grey, 2006). The great majority of these women have histories of child neglect and trauma. I have been pleading for 15 years for this reality to start to be honestly reflected in the information we disseminate publicly -- preferably replacing the guff about the difficult nature of this 'cohort of intractable females'. Again, it seems incredibly obvious to me that pedalling only derogatory information concentrating on 'management' of supposedly difficult behaviours with little or no balancing information that supports women's rights, given their circumstances, to at least have their 'behaviour' understood is unethical. However, there has been enormous political resistance to being candid. Why? I have given this considerable thought and I don't have an answer. Mental health systems around Australia deal incredibly badly with the adult implications of childhood abuse and trauma and I suspect that there is such a huge black hole here that a major re-structure of where our public money is being spent scares people and systems so much that they shut their eyes.

Perhaps there is some resistance to naming it as a particular problem for women with this diagnosis because we might be seen as disregarding the trauma and neglect histories of people (both men and women) with different diagnoses? There is an increasing body of evidence to show childhood trauma is an aetiological factor in psychotic disorders (Read et.al. 2006) for example. Perhaps we are trying to respect survivors of abuse who have done OK or really well as adults and, sharing the community's discriminatory attitudes towards mental illness, don't want the community to link childhood abuse with adult mental illness. I think this is an example of stigmaphobia but it might also be an example of survival. Perhaps it is out of respect for the 'carer' movement, which is struggling with this issue and largely failing to come to terms with the staggering statistics in relation to child abuse and neglect amongst women labelled in these ways. I think this dissonance between what many consumers tell me they need to hear and what many parent carers, involved in self help groups and active in the carer lobby, can bear to hear, retards the development of public policy in this area.

I'm not sure but after hearing women's stories of being silenced I cannot condone our continued misrepresentation. The level of childhood trauma amongst this group of women is significantly and disproportionately high. When you multiply this pain with a totally inadequate mental health system where women with this label frequently report re-abuse and a failure to even try and help our integrity as a society is diminished.

### **CONSUMER PERSPECTIVE**

Up until recently I was convinced that I had a grasp of these issues and then a transformative incident happened after I gave a talk in Melbourne. A young woman came up to me after the talk and she simply looked at me and said, "I wish I had been abused as a child". I didn't know what to say at first and I thought it better to say nothing and listen. This young woman had been diagnosed with 'borderline' and she was obviously distressed. She was covered in scars on her forearms, which was the only place I could see. After talking to her it was obvious that it was the paralytic shame about being responsible for her own 'badness' that seemed to be so profoundly disabling. Talking to her it was impossible not to think about the extraordinary array of shame-based literature stuck on 'guilt trips to conforming behaviours' that is available on 'borderline'. She wanted a story of abuse because then, she thought, there might be some sort of reason, some sort of rationale for her self hate and some explanation for her 'badness' and I just felt for her and realised that I had inadvertently contributed to her distress.

This is a good story to learn from because it reminds me of my consumer roots. Consumer politics is about the first person voice and lived experience and this is relative. It doesn't make me change my analysis and stop fighting for the many women who have been abused, neglected and traumatised as children and who end up in the mental health system, labelled as having 'borderline', and again neglected, sometimes re-abused. The link to childhood trauma (Grey, 2006; Emerson 2005; Epstein, 2005) is imperative but so too is the life of this woman and I don't want to contribute to her shame and, through this, to her profound distress. In much the same way I have, since that incident in particular, thought a lot about the men who get diagnosed with 'borderline'. They must be so lonely. They are in the minority but there is a very high incidence of childhood trauma and abuse in their histories too. As consumers we respect the differing lived experiences of all people; we respect their stories. Men with 'borderline' might be in the minority but this doesn't make them or their stories any less important.

Once again, this does not mean that I divert my attention away from the fact that 'borderline' is a women's issue and much of what we see happening in relation to it is about our society's incapacity to understand and respect women who do not behave like 'real women'.

### **CONCLUSION**

This is some food for thought. It is, in part, a call to arms for all of us who are interested in issues to do with the way women labelled with 'borderline' are treated, and not treated, within mental health policy, service systems and society. Circumstances will not change until we demand change and visibility. There might be debates to be had about treatment modalities and the construction of legitimacy within medicine. Because of recent 'breakthroughs' in science, which have found adult brain changes as a result of childhood psychological trauma, things might change. I am not so interested in these things and I will let them go, knowing that the different clinical interest groups will compete for this territory and medical research will willingly (and excitedly) take a new interest in the area buoyed by the chase for 'hard science' and the dollars that go with it. My interest is in what I think are the more important political debates we must have in our efforts to wrestle control of the 'mental health' (not mental illness) agenda away from the medical elites who thrive on a conceptual understanding of psychological distress which categorises and divides people leaving many women with a 'borderline' label on the 'just' and 'only' scrap heap.

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<sup>1</sup>There are many conversations happening amongst people who have been labelled as having mental illness about what

collective noun we want to use to describe ourselves. There is understandable resistance to using the word ‘consumer’ for many reasons including the implicit assumptions that we all must be consumers of psychiatric services, its economic rationalistic overtones and references to a consumerist society. Many people prefer Psych. Survivor, which implies they are survivors of the psychiatric system perhaps, or survivors of psychological distress. I have used consumer here because it presently has currency in Australia. This does not suggest that it is my preferred language.

<sup>2</sup> For a discussion of why I choose to use the term ‘labelled as having ‘borderline’ see Epstein (2005)

<sup>3</sup> The use of this language was first brought to my attention by Melbourne psychiatric survivor David Webb

<sup>4</sup> Third person voice is the more familiar research to most people. This is the research and the literature that is written about us (consumers/psych. Survivors) by others rather than about us by us.

<sup>5</sup> He is not saying that all knowledge lies in the consciousness of the individual person. Rather, he is arguing that to neglect this knowledge almost entirely as being ‘unscientific’, as is so often the case presently, is to lose half of the essential knowledge that is needed.

<sup>6</sup> Analytical and methodologically well argued. This does not mean consumers being always critical of ‘the system’.

<sup>7</sup> With its collaborative and consumer driven methods the Understanding & Involvement (U&I) Project and its three-year evaluation of psychiatric hospital practice won the Gold Award in the partnership category at the THEMHS Conference in 1996.

<sup>8</sup> Cartoon drawn by Dr. Brian Moench, creator of In Your Face Cards and published and distributed by The Ink Group, 904 Bourke Street, Waterloo NSW 2017

<sup>9</sup> ‘Mad Folk’ is language I first heard used by consumer, Anne Olsen, in the 1990s.

<sup>10</sup> This understanding that knowledge is power and taking care that knowledge is shared is a key platform of consumer politics. .

<sup>11</sup> ‘Deep Dialogue’ was a term referred to in two significant, consumer run projects of the late 1990s – the Understanding & Involvement (U&I) Project (Victorian Mental Illness Awareness Council) and the Lemon Tree Learning Project (Victorian Mental Illness Awareness Council). It describes the bringing together of people with diverse and sometimes oppositional views, roles and experiences in meeting places that are not about decision-making. It is about the provision of opportunities to have a conversation that is ‘deep’ but safe enough for all people to get involved - past the superficial, the party line, the expectations of bureaucracies and service organisations or clinical affiliation loyalty – also past the effects of exhaustion, deep hurt, guilt, ideology, helplessness and cynicism. The Deep Dialogue Project won the THEMHS Gold medal in the Partnership Category in 1999.

<sup>12</sup> There’s a growing body of work, which shows that women from lower class backgrounds and with poorer levels of education are more likely to receive this diagnosis. (See Paris 2005:1579)

<sup>13</sup> See Epstein (2005) & Epstein (2006)

<sup>14</sup> Including some who have a very keen interest in childhood trauma like Carolyn Quadrio (2005). There is an excitement that new research is finding evidence that suggests there is a physiological link between childhood trauma and adult brain changes. This worries me because it reifies even further the political idea that legitimacy comes only with scientific proof of illness.

<sup>15</sup> Castillo (2000) found that 88% of the people she talked to who had a diagnosis of BPD had experienced abuse. For 70% of women diagnosed with BPD this was early sexual abuse – the highest prevalence across gender/diagnostic categories.

<sup>16</sup> ‘Othering’ is a process that identifies those who are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination. See Johnson (2004).

<sup>17</sup> *Nothing about us without us* is the motto of the National Mental Health Consumer Network

<sup>18</sup> The Second National Mental Health Strategy has just been launched. All documents are available on the National Mental Health Branch website <http://www.health.gov.au/internet/wcms/publishing.nsf/Content/mental-strategy>

<sup>19</sup> However this is not just happening in Victoria. In 2004 I made a detailed study of the ‘Not for Service Report’ (Mental Health Council of Australia). In the body of the report there were 66 quotes about the damning ‘treatment’ of people labelled as ‘borderline’ (from consumers, carers and clinicians) in mental health systems across Australia. Every State and Territory was represented. Some of the stories were very horrifying but perhaps equally worrying was the fact that despite the volume of critique from the community there was a total absence of these issues in the summary and recommendations of the report.

<sup>20</sup> Note that so-called ‘care’ might be seen as a euphemism for being locked up and forcibly ‘treated’ which many consumers define as abuse, hence the inverted commas.

<sup>21</sup> The Spectrum website is [www.spectrumbpd.com.au](http://www.spectrumbpd.com.au)

<sup>22</sup> A study of the language of ‘seriousness’ since the publication of the First National Mental Health Strategy is intriguing. When it was used in this Strategy it was undefined. Within months of publication lobby groups representing psychotic illness grasped this undefined term. They were the most organised political lobby in Australia at the time for good reason. Services for people with psychotic illness had historically been abysmal. Within a year this pitch for

naming rights started to have a noticeable affect in that the descriptive adjectives had become a proper noun in the literature, in policy and in service delivery information. Instead of serious mental illness it was now Serious Mental Illness: meaning psychotic illness. Within a year this had become institutionalised and the acronym SMI had currency. Throughout the late 1990s and early 2000s it was interesting to watch as the politics played itself out in contemporary language usage in public policy. 'Serious' was replaced by 'severe' and then, 'severe and enduring' and then 'low prevalence' and then 'complex needs' which was the closest we got at a policy level of including the experience of women labelled with disorders such as 'borderline' as something that was indeed serious – which, of course, we all knew it to be. The recent publication of the Second National Mental Health Strategy has returned to the language of 'Severe Mental Illness'.

<sup>23</sup> Private psychiatrists often don't want anything to do with us or are booked out till the next millennium if they do happen to like us and are prepared to bulk bill or charge something we can afford to pay. Private psychologists are often inaccessible because the costs are prohibitive. Even with the newly found National Mental Health Strategy money released to enable people with mental distress access to psychological services, we are invisible. **'Borderline' is not on the list of acceptable diagnoses to be eligible for this 'new money'**. The only way for people with a primary diagnosis of 'borderline' to get psychological help through this new funding is for the psychiatrist/ GP and the psychologist to collude and lie or use our 'real' illness even if this is not our primary diagnosis. This is probably easy to do but it does not solve the political problem. In drafting this policy extraordinarily political decisions have been made about which diagnostic groups 'deserve' psychological services and which do not regardless of need.

<sup>24</sup> This reference is to the wit of David Webb.

<sup>25</sup> This can be either good or bad. As much as so many women labelled as having borderline are desperate to be taken seriously many other people who are labelled as having psychotic illness, for example, are desperate not to be locked up against their will and forcibly injected which are common corollaries of being taken seriously given present service assumptions.

<sup>26</sup> There is some conceptual confusion around whether you are focussing on the intent of the DSM or whether you are focussing on the effect of the DSM for consumers diagnosed with 'borderline'. The intent as I understand it is that the DSM classification system identifies disorders of the brain. Some of these disorders are viewed, by the authors, as illnesses – that is as a sub-set of all possible disorders. These illnesses can be identified and classified. Those 'conditions' that are not illnesses are still known as disorders. The lived reality for many people however is that the DSM works in an exclusionary way and that the disorders -- (predominantly) so-called personality disorders -- are the leftovers after the 'illnesses' are taken out.

<sup>27</sup> In my case they were both clinical psychologists registered with Victorian Psychologists Registration Board and members of the Australian Psychological Society (APS) but I have had equally damaging responses from psychiatrists – one of whom diagnosed me and then almost immediately kicked me off his books saying, "I don't treat 'borderlines'". He threw me back into the public system although he must have known that that this might well lead to total disaster. Which it did.

<sup>28</sup> Many consumers both nationally and internationally also despise this language. They dislike having their personalities pathologised especially when it appears to them that what should be pathologised are the circumstances which so unutterably affected their lives when they were young – too young to protect themselves. The perpetrators should be pathologised and the community that did not protect them should be pathologised. Judith Herman suggests that the set of symptoms representing the distress that gets labelled 'borderline' should be called Complex Post Traumatic Stress Disorder to better reflect the reality of people's circumstances. I have wondered in previous work (Epstein 2005) whether changing the label would in fact change the vilification attached to the label. I'm not sure.

<sup>29</sup> She has now produced an excellent short film about these issues. It is called, *The Waiting Room*.

<sup>30</sup> Ron Coleman is a leading consumer activist from Scotland. He was the keynote speaker at the THEMHS consumer day, 2006.

<sup>31</sup> Propaganda from drug companies, medical gurus, private healthcare companies (in the US) and so on.

<sup>32</sup> Sisters' Inside conference, Brisbane 2006

<sup>33</sup> For specific examples of this see Epstein (2005) & Epstein (2004).