

“Let’s face it! She’s just too f***d” – the politics of borderline personality disorder.**

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A Story to Start

In the mid 1990s I was representing the National Community Advisory Group (NCAG) on mental health at a National Mental Health Strategy meeting. An eminent psychiatrist with a senior position nationally sidled up to me at tea brake and advised me to let go of my resolve to bring the neglect and maltreatment of people diagnosed with borderline personality disorder out into the open. He justified this by saying, literally, “let’s face it they’re just too fucked!” I couldn’t believe it, especially since later that day we were talking about the language around ‘seriousness’ and it became increasingly obvious that this group of women did not fit into any past or anticipated framework of serious mental illness. To this day it totally mystifies me how the same group could be considered both ‘too f*****d and not serious!!

This incident has been amongst a small number of influential moments that have driven me to continue my fight for the rights of women diagnosed with Borderline Personality Disorder or BPD. In the time I have with you today I will argue that those of us fired up with anger about what happens (or does not happen) for people who receive this insidious diagnosis need to join together and get political. Quite frankly, no one and no group can do it without help. Apart from anything else it is fraught with the normal contradictions of life and these need resolution. However, I do have some knowledge now that I hope will be useful for others. All my understandings come from first hand, grass roots activism and many things I have tried have hit horrible brick walls: ideological, professional, political and practical. I will mention some of these in a minute but I want to start on a more positive note. For me, moving my anger from the wholly personal to be inclusive of the political was a very healthy thing to do. Joining together and getting angry with others and demanding change is difficult, but it is also empowering. Personal support groups are important but many of us have found forging ahead into radical critique and systemic advocacy is also a fundamentally useful way of looking after ourselves.

I want to explore some of the central issues that compound the situation for women labelled as having borderline in the judicial and forensic systems in which mental health services are interwoven. It is imperative that I qualify my contribution by saying that I have never been personally caught up in the system or been in jail.- by the grace of the goddess go I. Neither do I know a great deal about this interface from a professional or legal standpoint, however, I think I can make a contribution as a consumer who has been labelled as having borderline personality disorder and who has suffered awful consequences because of it.

I want to explore some of the wider philosophical, ethical and theoretical determinants of the situation I believe we now have where women's pain, when it is expressed through the so-called symptomology of borderline, is punished and cruelly dismissed within a mental health system, which is supposedly there to care. My central argument will be that the collective history of this marginalised and invisible group reflects assumptions about gender and that the central canon of psychiatry, the DSM 1V, has a political effect that permits compassion for 'medical illness' and denies suffering that goes to the heart of the fabric of institutions we are part of and perpetuate. I'll try to briefly explore something that has entertained my mind for some time and this is the paradox that emerges when proof of pathology is a pre requisite for resource legitimacy and an entrée to service provision. How do we resolve the tension that exists between demanding services for desperate women and at the same time maintaining a critique of blatant psychiatric imperialism? I will also focus a little on the complex task of 'bearing witness' to trauma and abuse and ask, can a system predicated on a 'medical model' of human suffering ever articulate the needs of survivors?

Language (i) – 'consumer'

I will be using the term 'consumer' to describe myself in relation to the mental health system. I do not personally like this word as it suggests a degree of choice in services that people labelled as mentally ill rarely enjoy. It also has overtones of economic rationalism that I find distasteful. Nonetheless I continue to use it out of respect for a fledgling social entity of people diagnosed with mental illness in this country. I see this broad coalition as the seeds of a diverse social movement akin to the women's movement and the gay and lesbian movement. It has formed around an agenda demanding social, legislative, and moral reform. Like the gay and lesbian movement it also shares the concept of 'coming out' in a cultural context that is often hostile and judgemental. If you find this word really irksome I beg you to suspend your judgement for a while. In time we'll find a new language that is more radical and self-determining.

Language (ii) – 'political'

I also just want to mention briefly how I am using the term 'political'. I am not referring to the politics of political parties. Rather, I am talking about social and personal forces, which are manipulated as different people, and groups of people try to gain greater influence and social power. For example, I am assuming that everyone in this room has a shared political agenda of getting more resources and a better deal for women labelled as having borderline personality disorder.

Language (iii) - People labelled as having borderline

The other thing that I want to briefly mention is my core interest in language. My language preference is to describe all of us who have been 'diagnosed' with Borderline as *'people who have been labelled as having borderline personality disorder'*. This will be unfamiliar to some of you and may seem a bit clumsy but it is fundamentally important to

me partly, but not wholly, because I reject the label personally. It is also for the following reasons, which for me are sacred:

1. It suggests the naming language of psychiatry has emerged from the classification urges of the mental illness industry rather than from any consultation with us;
2. It offers recognition of the experiences of many of us who acquire a borderline personality disorder label along with another ten or so different labels as we make our way through mental health systems;
3. It suggests the experienced ‘truth’ that many consumers cop a borderline label as punishment;
4. It questions the ‘thingness’ of borderline;
5. It registers my discomfort with medical language per se.; and
6. It is what the consumer movement calls ‘people first language’, that is, the emphasis is on personhood rather than on the illness or disorder.

The Little Purple Book

I think this is going to age me dreadfully but who in here is old enough to remember **The Little Red Book?** Quotations from Chairman Mao Tse-Tung. I remember my older sister and I getting a copy of it when we were both still at school. We thought we were very brave and a little hip having managed to procure one.

Very early in my days as a consumer activist I also procured **The Little Purple Book**. I like to think of this as a young women’s version of their own feminist manifesto. It was put together by the Young Women’s Group, which was a group for young women with mental health problems who were homeless. The Little Purple Book was to have a profound and enduring impact on my future in mental health. Like The Little Red Book it was pocket size. The women had insisted on that because they wanted 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. It was the radical intent of this unassuming document that first alerted me to the systemic and institutionalised discrimination faced by women given this diagnosis. It is a very sad but imperative read. The group was empowering and authentic. Predictably, it also failed in all its efforts to get ongoing funding.

I will always remember one contribution. It simply said:

*“I thought I would write my life story
but instead
I am just going to photocopy my arms”¹*

Labelling

Judith Herman, an American psychiatrist and someone who is admired by many consumers, has called borderline personality disorder a ‘sophisticated term of [patient]

¹ Young Women’s Group, *In a Nut Shell*, no date

abuse’² Consumers argue strongly that the best way to arrest the defamation that so often follows this label is to emphasise the close correlation between adult experiences which get labelled borderline personality disorder and childhood experiences of trauma, abuse and/or neglect. Herman’s ‘complex post traumatic stress disorder’ is liked by many consumers for good reason. Others argue that that it is not useful because there are about 10 - 15% of people with this diagnosis who don’t have personal histories of trauma.³ Others argue that it needs to be placed within a spectrum of conditions that could be called ‘Trauma Spectrum Disorders’ (including Dissociative Identity Disorder (DID) – the old name was Multiple Personality Disorder and Post Traumatic Stress Disorder.(PTSD)⁴

I don’t like labelling people and I particularly don’t like medical descriptors of people’s personalities. I think this is one of the reasons why I have such reservations about all this new political speak about early intervention in mental health. You know, I heard a respected ‘expert’ say the other day that we should be starting to pick up the early signs of ‘borderline’ in children from six months to six years. How horrifying is this!! I know, however, that many consumers believe the gaining of a diagnosis is empowering. This tends to, but does not absolutely; follow the legitimacy and ‘status’ of different categories of distress. Bi-polar affective disorder, for example, is one diagnosis that many people want to use because 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 that follows the diagnosis intensifies some people’s self hate and subsequent symptomatology in my experience. Persimmon Blackbridge, a Canadian consumer, wrote the following in her terrific book, Prozac Highway.⁵

“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.”⁶

I love this quote. 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

²Herman 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

³ 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

⁴ Therapeutic Case Management for Borderline Personality Disorder (unpublished), Mental health Commission of New Zealand, 2004

⁵ Blackbridge, P. 1997, Press Gang Publishers, Vancouver p. 32

⁶ 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

things like; “mention I have been diagnosed with schizophrenia and depression but please don’t say anything about borderline.”

Women and Borderline

Many of the psychiatric labels tend to be gender sensitive; however, this is particularly apparent with people diagnosed with personality disorders. In a special addition of the journal, *Asylum*, published in 2004 there are some extremely powerful contributions from women labelled as having borderline. The Edition is called BPD but instead of this standing for Borderline Personality Disorder it stands for Bullshit Psychiatric Diagnosis. I have a leaning toward this sentiment especially as I have seen so much damage done to women in **and out** of the mental health system who carry this dubious diagnosis. As a woman who has worn this label it is imperative that I make the point right now that **the mental health system is not a safe place for us**. Any fantasies held by people outside psychiatry that *asylum* is a possibility for women with this diagnosis need to be quashed immediately.

Over 75% of people diagnosed with borderline are women and Castillo found in her research in Britain in 2000 that 88% of women she spoke to who had a BPD label were adult survivors of childhood abuse. There is also an extremely high incidence of family violence and sexual assault in the background of women who are labelled in this way. Given this, there is no doubt in my mind that borderline is a women’s issue. **The mental health sector deals extremely badly both with issues to do with women and even worse with issues to do with childhood trauma**. One of the most worrying examples of this in Victoria is that we have no women only acute units. Can you imagine being one woman with a history of sexual abuse being locked up in a small seclusion unit for hours or even days with five distressed males? How could this possibly be therapeutic?

Desperate for services

The failure of the mental illness industry to think about, let alone deal satisfactorily with, these fundamental social issues is a major problem. The dominance of a medical model of understanding human distress individualises and pathologises. It then sets up a competition telling people that they will only get a service if they can prove they are ‘sicker’ than the person next to them. People with certain diagnoses have an advantage in this game of seriousness. Even when people labelled as borderline try to demonstrate their distress their label works against them and they are instantaneously seen as non-genuine and non-rewardable. No services are granted and the process escalates often out of control. There is no incentive to be OK and independent and then women are accused of being not OK and dependent. For many women it is a crazy wheel of further abuse that blames them and de-politicises the social issues that are fundamental to their sanity. I also have no doubt that there are issues of social class associated with this diagnosis as class as well as gender.

In *Bullshit Psychiatric Diagnosis*, Clare Saw and Gillian Procter write:

BPD has always been a diagnosis of exclusion from mainstream mental health services, women are marginalised and stigmatised within services by descriptions such as manipulative, attention-seeking nuisances. Women are punished – sutured without anaesthetic in A&E; marginalised in society – women have their children removed, and fall between benefits – often unable to claim disability benefits but too distressed and stigmatised to work.⁷

Borderline as a brain disease

People argue that if we find another term and get rid of the harmful meanings imbedded in the term, 'borderline', the new term 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 all just as distressed people?" This is a good question. I have spent many hours thinking about it. The obvious first response is that doing so would be to abandon the idea of medical science as we know it as it is singularly predicated on the idea of diagnosis followed by treatment. Many people might find getting rid of a 'medical model' for understanding mental distress a jolly good idea but I think we might find some opposition to this.

It's all about funding. Governments, particularly in first world economies, 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. This presents all manner of very practical problems for people where the source of their distress, is, by evidence-based measures of malfunctioning brains alone, questionable.

And there are few more evidence-obsessed systems than the legal system – it may be that a new label could serve to end much of the discrimination, abuse and damaging dispositions this diagnosis attracts in the legal system if the renaming is accompanied by a radical reshaping of the mental health service system's approach, and an end to the alarmingly and, it seems, increasingly retributive nature of the criminal justice system. As, indeed is the case for all people with mental illness, disability or extreme socio-economic or other disadvantage caught up in the criminal justice system (is that everyone?), women with a borderline label will only receive justice when the legal system is based genuinely on actual moral responsibility, and fair dinkum diversion to where responsibility arguably lies – currently dysfunctional, discriminatory social and mental health service systems.

Carolyn Quadrio⁸, a professor at the University of NSW Department of Psychiatry and others with a background in medical science are now arguing, with the help of empirical data, that childhood trauma actually does change brain functioning in a way that can be

⁷ "Saw Clare and Procter Gillian, Women at the Margins in Bullshit Psychiatric Diagnosis – Women and Borderline Personality Disorder in Asylum Volume 14 No. 3 p. 3

⁸ Quadrio Carolyn, Axis One/Axis Two: A Disordered Borderline in, Psychology, Psychiatry, and Mental Health Monographs: The Journal of the NSW Institute of Psychiatry Volume 2: November 2005 pp 141 - 156

‘scientifically’ identified and quantified. Politically this is very helpful. It enforces our campaign for greater resources and acceptance, and then, hopefully, will have the flow on effect of leading to a greater respect and tolerance of so-called borderline traits and symptomology within a health system that defies brain disease science. It also wets the appetite of drug companies and with this the possibility of all sorts of economic opportunities we might or might not want.

I remain wary of such emphasis although I admire Carolyn Quadrio’s work and passion in this field. One of my greatest anxieties is about the ‘evidence-base’ industry, which is presently flourishing. It concerns me that we will use so-called science to create ‘easy evidence’ to promote therapies that justify dragging even more people into a drug-dependent ‘medical model’ framework or, just as dangerously, into simplistic behavioural therapy regimens with which some clinicians, researchers and funders are presently obsessed. The present clinical fixation on time limited interventions based on changing our ‘behaviour’ suits some but for many of us it can be an insult to both our intelligence and the depth of our pain. Perhaps I am getting old and jaundiced but I am sufficiently cynical to see its growing popularity as politically clever and cheap. These evidence-based interventions include both the well known, Cognitive Behaviour Therapy and the present borderline hit - Dialectical Behavioural Therapy or DBT. Clare Shaw, a survivor activist in Britain writes:

“We will not rest until the answer is not to prescribe DBT, the therapy most publicised and seemingly popular with workers, misguidingly being presented as the ‘benign’ response to BPD. Instead, it plays right into the agenda of the label, accepting it wholeheartedly along with the implication that women with BPD are damaged creatures who need to be saved by the professional and taught how to be more appropriate’. Again, DBT depoliticises and personalises the real issue. The real issue is the pervasive abuse of women and girls in this society, coupled with the continuing silencing and invalidation of women’s experience.”⁹

A real contradiction

However, there are real practical contradictions in all this. Important ideology notwithstanding I know people who have been labelled as having borderline who do not have histories of childhood trauma. Yes, they are by far the minority as are the men with a diagnosis of Borderline but nonetheless they are real people. Sometimes when these women read and hear arguments such as the one above they feel isolated and profoundly guilty. A couple of years ago a young woman came up to me after I had given a paper at a conference and she said to me, “I wish I had been abused as a child.” At first I was dumbstruck but then I got it. All she could see at that moment was that an abuse history would give her a coat hanger on which to hang her severe distress, desperate need to self-harm, helplessness and hopelessness. She felt she did not deserve the privilege of what she saw as a normal childhood. I later heard that that evening she so badly cut herself that she ended up admitted to hospital for three days. Some women with this label really are desperate for help and for whatever reason (including the absence of or ignorance about both alternatives and the reality of psychiatry) they turn desperately and deliberately

⁹ Shaw, Clare, Women at the Margins in Bullshit Psychiatric Diagnosis – Women and Borderline Personality Disorder in Asylum Volume 14 No. 3 p. 3

towards psychiatry. Representing consumers at this conference I feel a responsibility to defend every women's right to try and trust psychiatry if they want to even if they later become disillusioned. I just pray they don't get damaged in the process.

The Diagnostic and Statistical Manual (DSM IV)

However, there are things in psychiatry we all have a right to know. For starters there is the extraordinary influence of the American Psychiatric Association and the Diagnostic and Statistical Manual; more often simply referred to as the DSM.

I just want to spend a minute making sure that you all have a basic understanding of the power of the DSM. We are currently up to edition IV and very soon we believe volume V will be released. This document is like the bible for psychiatry. Clinicians are required to diagnose using its, often limited (in my opinion), description of symptoms, as if psychiatry is an exact science which I believe it is not.

It is particularly problematic for people with so-called personality disorders because the DSM IV divides people's pain and psychiatric/psychological distress into what it calls two Axes. The first one is reserved for what the authors regard as the 'real' psychiatric illnesses – the ones that many people within the consumer movement jokingly call the 'Capital I' illnesses – Schizophrenia, Bi-polar etc. By virtue simply of their position within this document these are the conditions that are seen to be 'deserving' of resource priority by definition. So-called 'personality disorders' on the other hand, sit with intellectual disability (would you believe) in a section that this 'bible' describes as AXIS II diagnoses. These are not seen to be proper mental illnesses and, as such, they are never seen to be deserving of resource priority. This volume is a major source of discrimination against people labelled as having borderline personality disorder.

In the criminal justice system, a diagnosis of borderline personality disorder will not allow a person to be found "not guilty" due to mental impairment, whereas Axis I labels will. Do we dare hope there is a model for useful reform in this sense in recent changes to Victoria's fine system which acknowledges that a person should have reduced culpability both where disability meant they did not know what they were doing (Axis I type approach on which mental state defences are based) and where disability was the reason they acted as they did? (perhaps Axis II type defence in the future.) Of course, the way courts attribute responsibility by finding people guilty or not guilty is just a small part of it - those who successfully argue this defence in Victoria are exceedingly unlikely to go to jail, but will end up on potentially indefinite custodial or non-custodial supervision orders. Criminal justice dispositions are unlikely to ever be appropriate while service system and social responses are not.

In terms of mitigation and disposition for people found guilty, many lawyers will advise clients to conceal this diagnosis if a more legally palatable one is available because of the often prejudicial attitude of the judiciary and legal system more broadly.

And the reality is that it is only a proportion of women with a borderline diagnosis who end up in prison – it is the discrimination and disadvantage which blight the lives of this

group more generally which is the bigger issue. People with a borderline label will find mental health services put more energy into limiting their access to services and implementing punitive management plans than providing useful services, and the list goes on – the same ignorance stigma and prejudice rife in the legal system permeates society as a whole.

Axis II diagnoses will continue to be the poor cousins whilst the DSM rules so much of our thinking in mental health. The somewhat curious relationship¹⁰ 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 Axis II diagnoses¹¹ 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 drug interventions and therefore of little economic interest.

I struggle with balancing this argument with the political realities for women mentioned previously. None of this is black and white and like any other disparate group, we stretch along a continuum in terms of where we position ourselves in relation to this debate. Do we want personality disorders to be described in the DSM as ‘real’, Axis I, mental illnesses? This would give us much greater legitimacy, hopefully eliminate some of the discrimination, offer us access to resources and perhaps fewer of us would end up in jail. However, at what cost? Many women labelled as having borderline are forced into services that are inadequate and damaging. Is this a gain? Do we really want more women subject to this? Others with this label are very relieved, in fact adamant, that their distress must not now, nor ever, be described as a mental illness. They argue that it is total crap to understand their totally understandable reactions to an awful life seen as illness. This is the argument put forward quite convincingly by consumers in the 2004 edition of *Asylum*. However, the most important thing here is to understand the role played by this extraordinarily powerful, political document; the DSM.

The unintended consequences of State Mental Health Acts¹²

There are also unintended consequences of the Victorian Mental Health Act for people labelled as having borderline. I’m not sure whether this is similar in other State and Territories. In setting criteria for involuntary detention in the State of Victoria, clauses have been added to minimise any possibility that the ‘wrong’ people might be trapped under the Act. There are several arguments about why this has been done and they include the knowledge (and the latest evidence including from *Spectrum*) that people with borderline have distress that will escalate if they are admitted to hospital especially

¹⁰ Especially for people who don’t live in or particular understand American culture.

¹¹ personality disorders

¹² 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 States. 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!

for long periods and especially involuntarily. However of equal importance is the attempt to protect the human rights of those who are 'just' loud, or eccentric, or different or who have strong beliefs and proselytise publicly etc.

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

“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.”¹³

I have an adamant position that the protection of people's human rights to the greatest degree possible must be unassailable. My psychiatrist and I have direct personal evidence that being imprisoned and treated against one's will, can and does, 'cause' mental illness. It is called Post Traumatic Shock Disorder. However, there are some interesting anomalies that come out of the way The Act is often 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 within the public system. With the everyday shorthand use of the term 'mental illness'¹⁴ to describe the target population it becomes incredibly easy for governments to manipulate the language so that people who aren't 'mentally ill' (in terms of the Act) will be left out with the subsequent saving of a significant amount of money;

Deinstitutionalised! Or are we?

Although we have supposedly all been desinstitutionalised we know this is not the whole truth. The mental health system is still a **system** and its epicentre is the acute unit where the image of 'the bed' is still the central currency of legitimacy.

The political reality then, 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 generalist community public service in Victoria is through a stay in a public hospital acute unit. People go from an acute 'bed' to backup community services.

So, the default position will be that those disorders that are not considered to be 'illnesses' and not seen to require 'beds', will be massively disadvantaged. This will continue to happen until governments recognise that real money must be taken away from doctors and hospitals and allocated through different routes: sexual assault centres, consumer run services, women's refuges, feminist counsellors and so on. If these alternatives were generously available women with very genuine psychological

¹³ Mental Health Legal Centre, Patients' Rights – A self-help guide to the Victorian Mental Health Act, May 2003 p.5

¹⁴ See SANE's website at <http://www.sane.org/>

needs might not be forced to become the bottom rung of the mental illness industry ladder.

We are hoping that the new mental health money come from Canberra in the budget for psychologists might help a little. Why I am so sceptical? I guess I am worried about medicare numbers leading to another group of health professionals bleeding the system. I know this sound awful. I hope I am wrong.

Survivor politics¹⁵/consumer politics

Survivor politics in Australia is a bit confusing. Historically the survivor movement has represented people who have survived childhood abuse; however, internationally the more radical end of the mental health consumer movement is also called the ‘survivor’ or ‘mental health survivor movement’. When I talk about the survivor movement here I am talking about survivors of childhood trauma and abuse who have organised themselves to form a lobby group to pressure governments about policy and practice especially in relation to childhood abuse issues. These groups often don’t want the general public making an automatic assumption that childhood abuse equals adult mental ‘illness’.

There are two important points in relation to this:

- There is no good reason why people who are active in survivor politics would have any less a stigmatised view of ‘mental illness’ than anyone else. The same misunderstandings and prejudices are just as likely to exist within the survivor movement as elsewhere in society.
- For some, the philosophy of survivor politics is that the issue of child abuse is not about individual pathology at all, indeed the suggestion of pathology is an anathema. Rather, there is an insistence that the emphasis must always remain on the social imperative that the abuse of women and girls must stop. The change therefore need to be in the society not in the women. The pathology is in the men (and a few women) who cause this harm to women.. This is extremely well articulated in much of the feminist literature. For some of these women if there is to be intervention it is more likely to be counselling in empowering and self actualising, often feminist ways and preferably not by health professionals. Part of this politics for some is that a model of individual pathology feeds into a dangerous social misconception.

On the other hand those of us who have been labelled as having BPD and have found ourselves discriminated against, excluded from, and defamed within the mental health system because they say we don’t have a ‘real’ mental illness and are using services that we don’t deserve and which should be going to people with schizophrenia have political needs that are sometimes quite different from this. We need to be accepted as ‘genuinely deserving of services’ and within a model of understanding distress that privileges brain disease we have to (sometimes for survival) claim ‘dis –ease’ as loudly as we can. Even, when as part of a consumer movement we might want to critique the ‘brain disease’

¹⁵ 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.

model of understanding our emotional distress we have learnt that unless we fit into it we alienate ourselves from the political decision making and we are scared that this will jeopardise future funding for young women who will follow. jeopardises 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 has the potential, unfortunately, to divide people who have similar experiences and split the potential for effective collective lobbying.

Mental Health Consumer Politics

There is also substantial discrimination against women labelled as having borderline personality disorder within the consumer movement in Australia. It has also been document in the mental health user movement in the UK and in parts of the US.

1. Consumers are no less influenced by the ‘mad’/’bad’ dichotomy than anyone else. Many consumers distance themselves from people who are labelled as having borderline because in the back of their minds is a fear that their reputation as ‘bad’ people might set back the campaign to fight discrimination against people with mental illness;
2. Whilst legitimacy is seen to go with psychotic illness or other Axis I diagnoses some other consumers will continue to see our (people with Axis II diagnoses) issues as less important;
3. The disputes around language are very real. Labelling disadvantages some groups and actually advantages others. There is important work we need to do internally (within the consumer movement) before we can launch a broader political campaign;
4. Whilst many of us remain cynical that there is even such a thing as borderline 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 borderline have demonstrated their distress. Self-harm can be quite alarming 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 and “f***d” women who have been labelled as having borderline really are. It should not surprise us that these attitudes follow them into the consumer political arena.
7. Borderline 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.
8. Many consumers associate borderline with criminality. They see women with this label rotating between drug and alcohol services, mental health services and forensic services. Sometimes they have not been told that one of the reasons people with this label frequently get caught up in the criminal justice system is that they are consistently refused mental health services.

Mad Pride

My friends and I consider ourselves part of a fledgling Mad Pride movement in Australia. In other parts of the world, the movements which represent people with mental illness, are often much more radicalised than they are in Australia. They openly fight the medical model. They fight the research establishment, especially research that part of it which is funded by pharmaceutical companies. They argue that forced treatment fulfils the United Nations definition of torture and fight to have this included in the legislature. They will no longer use the word 'force' and the word 'treatment' in the same sentence arguing that they are fundamentally opposed and they fight for consumer run services as providing the greatest hope of empowerment and recovery. They also don't use the language of consumerism because they are basically opposed to consuming any of the services churned out by the mental illness industry. They most commonly use the term, 'psychiatric survivor' rather than consumer. There are Australian consumers who do likewise although they are probably still in the minority at this stage. In challenging the existence of 'mental illness' at all psychiatric survivors extinguish the false and damaging belief that Axis I diagnoses are somehow more legitimate and more important than Axis II diagnoses. If there is no 'mental illness', or if all so-called 'mental illnesses' are seen as social constructs, then it doesn't matter if you've only got a 'personality disorder'. One of the outcomes of this political position is that all forms of mental anguish 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.

Conclusion

The population prevalence of so-called borderline personality disorder in Australia is approximately 1%¹⁶. This is strikingly similar to the population prevalence of schizophrenia.¹⁷¹⁸ Both of these experiences can be disabling and both are serious. Both have high rates of reported suicide. And yet, there is no comparison between the way they are prioritised in this country, depicted in the literature or treated in the mental health system. In the Not for Service Report published by the Mental Health Council of Australia in late 2005 there were quotes from consumers in every single State and Territory in Australia graphically portraying both the human rights abuses of women labelled as 'borderline' within the system and the tragic consequences of systems' failure to provide any sort of service at all for many. I read every page of that report and collected every reference to borderline. It was a pretty salutary read and yet there was no mention of these issues in the summation or recommendations. This is typical.

Those of us who are vitally interested in the lives of those who have been labelled as having borderline have a big fight ahead of us and this is not just a fight to procure even a

¹⁶ Henry Jackson & Philip Burgess' 2000, *Personality Disorders in the community: a report from the Australian National Survey of Mental Health and Wellbeing*

¹⁷ 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

¹⁸ Jablonsky A. et al *Psychotic Disorders in urban areas: an overview of the Study of Low Prevalence Disorders in Australian and New Zealand Journal of Psychiatry* 2000;34: 221- 236

basic level of service provision but also a fight to keep women out of jail and, importantly, make sure that services of the future do no more harm. This will require not only political will but also the forming of perhaps unlikely political alliances including and especially consumers and survivors and their organisations, carers, psychotherapists (who I have found to be singularly lacking in political instinct), non-government organisations, other interested clinicians and anyone committed to demanding change. Nothing will happen unless we get ourselves organised and both learn from and educate successful lobbying organisations such as SANE and the Mental Health Council of Australia (MHCA). Our fight must include a critique of the 'system' as we know it but I tentatively think it must also involve balancing pragmatism and ideology. Is this a compromise worth making if we are going to make a real difference to people's lives? I'm not sure but I hope so.