

“Borderline Personality Disorder” – Diagnosis of Shame

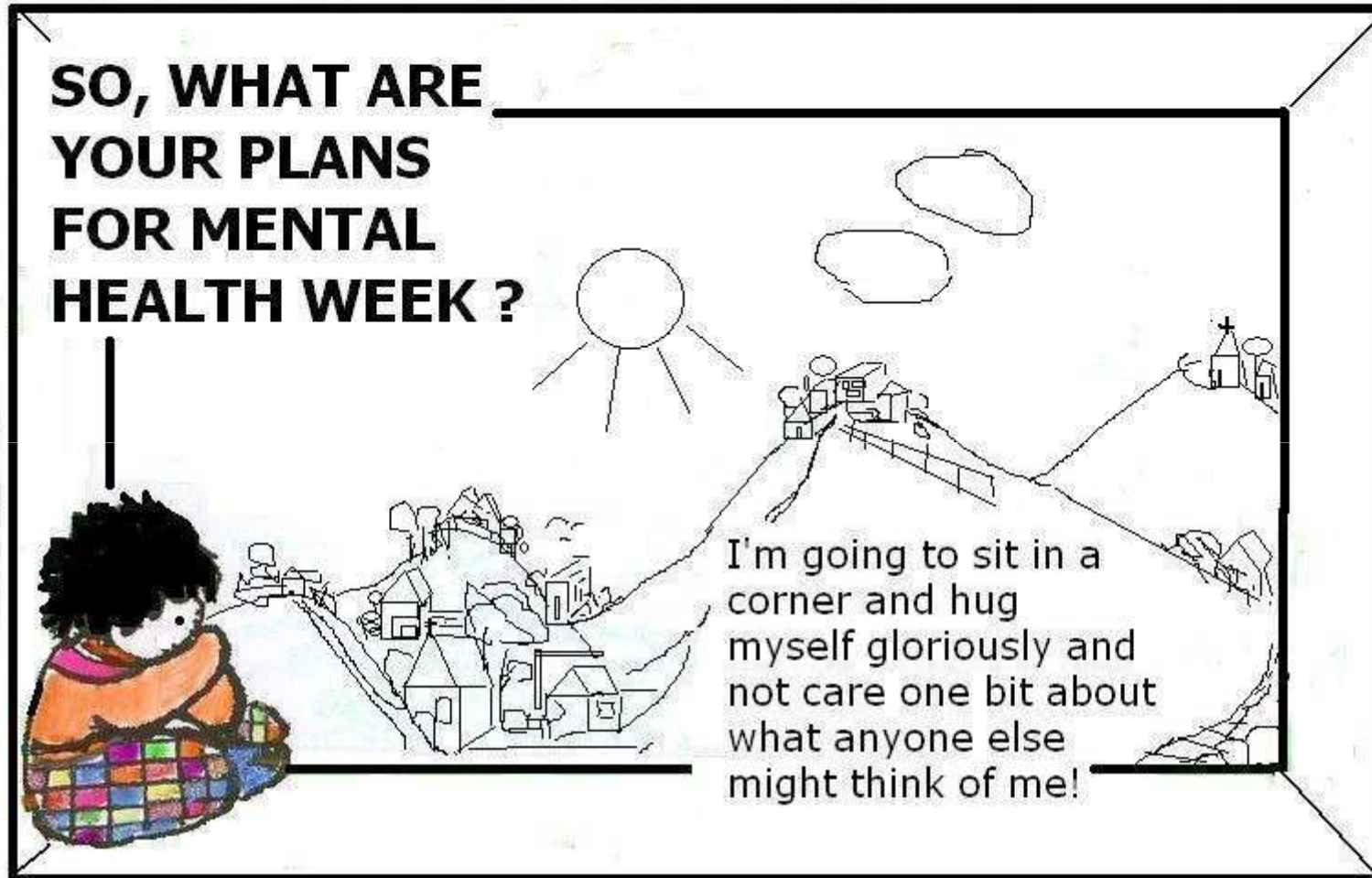
Merinda Epstein - Our Consumer Place



**SO, WHAT ARE
YOUR PLANS
FOR MENTAL
HEALTH WEEK ?**



I'm going to sit in a corner and hug myself gloriously and not care one bit about what anyone else might think of me!



BPD

Beautiful

People

Denied

Bullshit

Psychiatric

Diagnosis

From Magazine For Democratic Society 2004

In a Nut Shell

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

FINDING THIS LITTLE PURPLE BOOK AND FIGHTING (unsuccessfully) FOR THE CONTINUENCE OF FUNDING FOR THE 'YOUNG WOMEN'S GROUP' WAS THE START OF MY JOURNEY FIGHTING FOR THE RIGHTS OF PEOPLE LABELLED WITH BPD. IT WAS 1991.

Young Women's Group, *In a Nut Shell*, 1991

Contents:

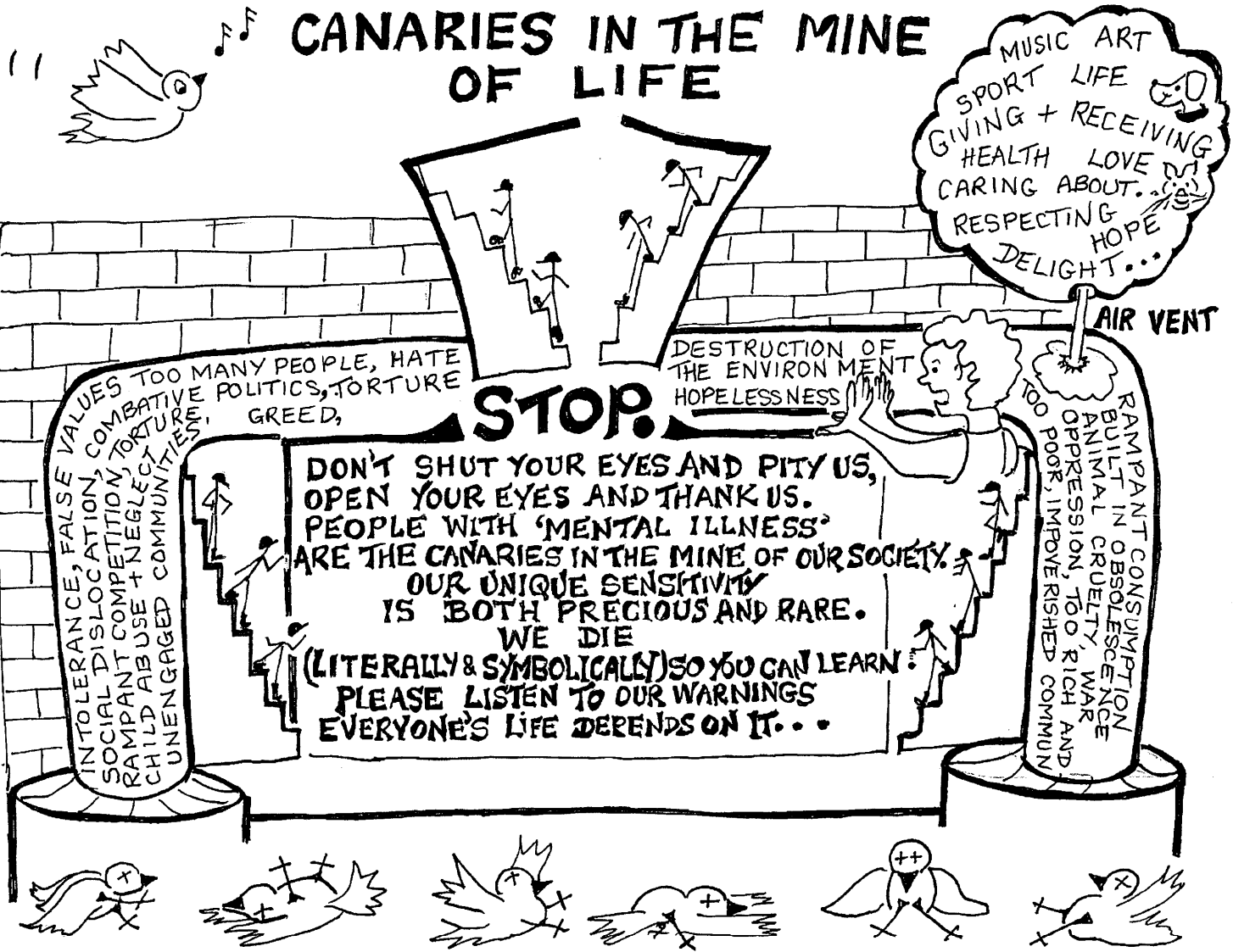
- 1. Websites**
- 2. The label & the diagnosis**
- 3. Common myths**
- 4. Some new thinking**
- 5. Just to touch on A&E and self harm**
- 6. Oppression, prejudice –just to touch**

Far too much to say... far too much to do

1. <http://www.takver.com/epstein/>
2. <http://www.ourconsumerplace.com.au/consumer/index>
3. merindae@ourconsumerplace.com.au

5 IMPORTANT METAPHORS: Consumers describe Borderline

1. Emotional Haemophilia
2. Lacking an Emotional Skin
3. Fear and Panic Button permanently with the ON button on.
4. The canary in the mine
5. I'm a cesspool of shame



The Label and the dilemma

1. Some of us hate it and it works for others;
2. DSMv – 2013: it's in as Axis 1 - does this make any real difference?
3. Do we want to be seen as having a 'Serious Mental Illness' – don't count on it.
4. If you're a clinician and you hate the label but have to use it for bureaucratic reasons – tell us;
5. Language is what you use to think with. Don't diagnose us with BPD and not tell us to protect us from the label. It won't work.

If you genuinely hate the label give us a few alternatives to choose from.

1. **Judith Herman's: 'Complex Post Traumatic Stress Disorder'.**
 2. **WHO ICD-10: Emotionally Unstable Personality Disorder-Borderline type**
 3. **Chinese Society of psychiatrists: Impulsive Personality Disorder**
 4. **Leland Heller: Mercurial Disorder Impulse Disorder or Interpersonal Regulatory Disorder**
 5. **Marsha Linehan: Emotional Regulation Disorder**
 6. **Carolyn Quadrio: Post Traumatic Personality Disorganization**
- *(Remember, some of us will reject all of these but its our choice)*

What the 'Borderline' Diagnosis means to some consumers

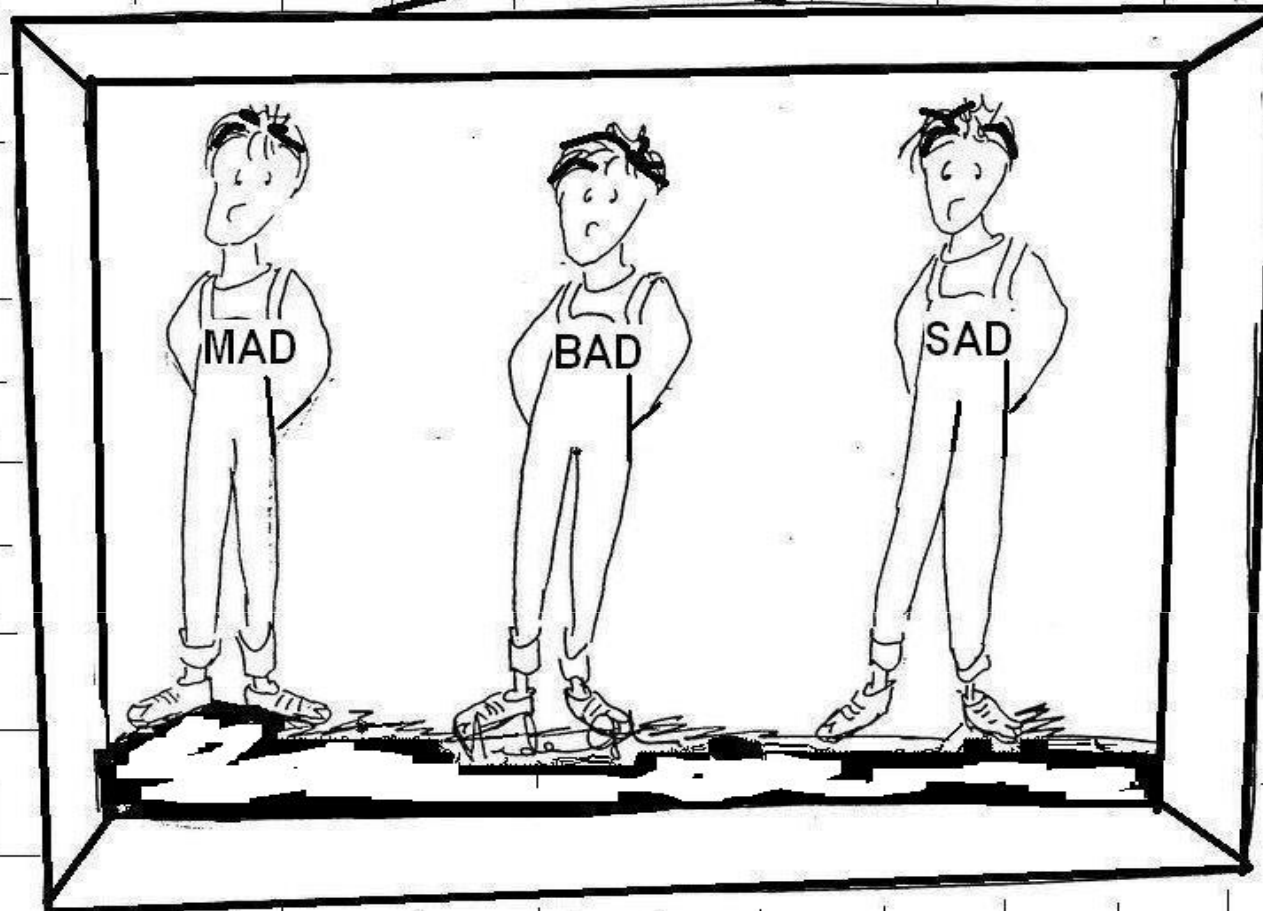
1. **'It means I am a bad person.'**
2. **'I do not have a proper personality.'**
3. **'I only have half a personality'.**
4. **'I am losing my personality'.**
5. **'I never got a proper personality when I was young'.**
6. **'I am not a real person',**
7. **'I am personally responsible for everything that goes wrong because its all my personality's fault.'**
8. **'Borderline means it is all just behavioural.'**
9. **'My pain isn't really bad – I am.'**
10. **'My personality is horrible no one will ever like me;'**
11. **'My personality is horrible no one will ever want to help me.'**
12. **My personality is not formed properly and never will be;**
13. **My personality was only borderline developed. It will never grow any better than this.'**

IN ORDER TO BE TAKEN SERIOUSLY YOU
NEED TO PRESENT AS...



Merinda Epstein
1995

SERIOUSLY ILL



THREE FACES of DISTRESS
A study in medical judgement 2007

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Common perceptions/myths about BPD held by clinicians:

- 1. People with BPD are always difficult and demanding;**
- 2. People with BPD are incurable;**
- 3. People with BPD destroy the competence and confidence of clinicians, particularly inexperienced clinicians;**
- 4. People with BPD don't have proper/'serious' mental illness and their behaviour is just willful;**

More common perceptions/myths about BPD held by clinicians:

1. People with BPD split staff and see things as all good or all bad (black & white);
2. People with BPD are often untruthful and most of their behaviour is manipulative and designed to attract attention;
3. People with BPD use up a disproportionate amount of service time;
4. People with BPD displace much more needy clients/patients;
5. People with BPD create chaos wherever they go.

BORDERLINE PERSONALITY DISORDER

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**SPECIAL
OFFER**

**BLACK &
WHITE**

**IN-SIGHT
SAFETY
GOGGLES**

**USE WITH
STAFF-SPLITTING GUNS**

BORDERLINE PERSONALITY DISORDER
SPECIAL OFFER
STAFF-SPLITTING GUNS



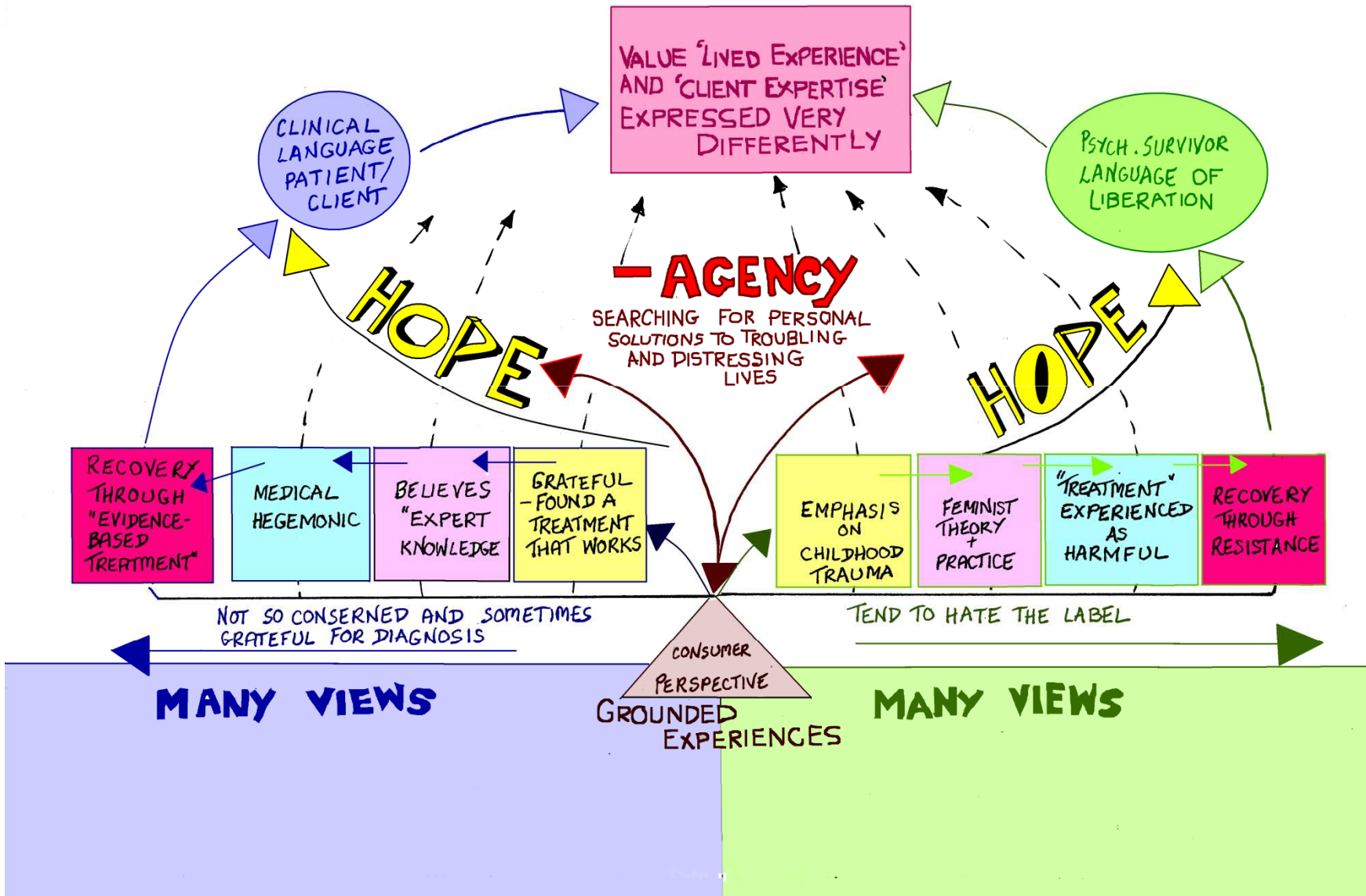
EASY TO USE, HEAVY DUTY, LIGHT.
SINGLE & DOUBLE BARREL MODELS AVAILABLE

What speaking to hundreds of people (over 20 years) with this label has taught me:

1. Although the label of BPD is spurious for some the deep shame & distress is not.
2. People labelled as having BPD are often treated with disdain by 'helping' agencies.
3. Sometimes people with a BPD label live non-gender stereotyped lives confusing and angering too many workers and clinicians;
4. Clinicians and workers sometimes behave from a place of fear which leads to more chaos and distress;

Important messages people diagnosed with BPD have told me...

1. Childhood trauma is pervasive amongst people with a BPD diagnosis – it must never again be the elephant in the room.
2. A 'personality disorder' diagnosis is often given as a punishment when people seem to be ungrateful, non-compliant, challenging –rarely are these attributes seen as the coping skills they often are.
3. Some clinicians/services blow their own trumpets because they 'treat' *'the most serious' cases*". This is at the cost of hundreds of people who can get absolutely no service at all;
4. The system teaches desperate people to self harm or hurt others without taking any responsibility for the consequences of this policy. This is negligence, perhaps legally negligent.



CLINICAL LANGUAGE PATIENT/CLIENT

PSYCH. SURVIVOR LANGUAGE OF LIBERATION

VALUE 'LIVED EXPERIENCE' AND 'CLIENT EXPERTISE' EXPRESSED VERY DIFFERENTLY

- AGENCY

SEARCHING FOR PERSONAL SOLUTIONS TO TROUBLING AND DISTRESSING LIVES

HOPE

HOPE

RECOVERY THROUGH "EVIDENCE-BASED TREATMENT"

MEDICAL HEGEMONIC

BELIEVES "EXPERT KNOWLEDGE"

GRATEFUL - FOUND A TREATMENT THAT WORKS

EMPHASIS ON CHILDHOOD TRAUMA

FEMINIST THEORY + PRACTICE

"TREATMENT" EXPERIENCED AS HARMFUL

RECOVERY THROUGH RESISTANCE

CONSUMER PERSPECTIVE

GROUNDUP EXPERIENCES

MANY VIEWS

MANY VIEWS

NOT SO CONCERNED AND SOMETIMES GRATEFUL FOR DIAGNOSIS

TEND TO HATE THE LABEL

The beginnings of a model. Consumers speak and write about how they find health

- **It's absolutely not absolute!** people pick and choose what they need from both sides of the schemata – jumping back and forward;
- **However, it indicates what could develop with more research to be real trends;**
- **There is no one way here. Some of us write about finding health both through (miraculously) obtaining good services/clinicians and others of us through totally resisting many mainstream services.**
- **The most important indicator of all is that people have agency; that is, they make their own decisions and take action based on those decisions (if they can)..**

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*If you have come here to help me,
you are wasting your time...
But if you have come because your
liberation is bound up with mine,
then let us work together.*

*Lilla Watson
Aboriginal Educator*

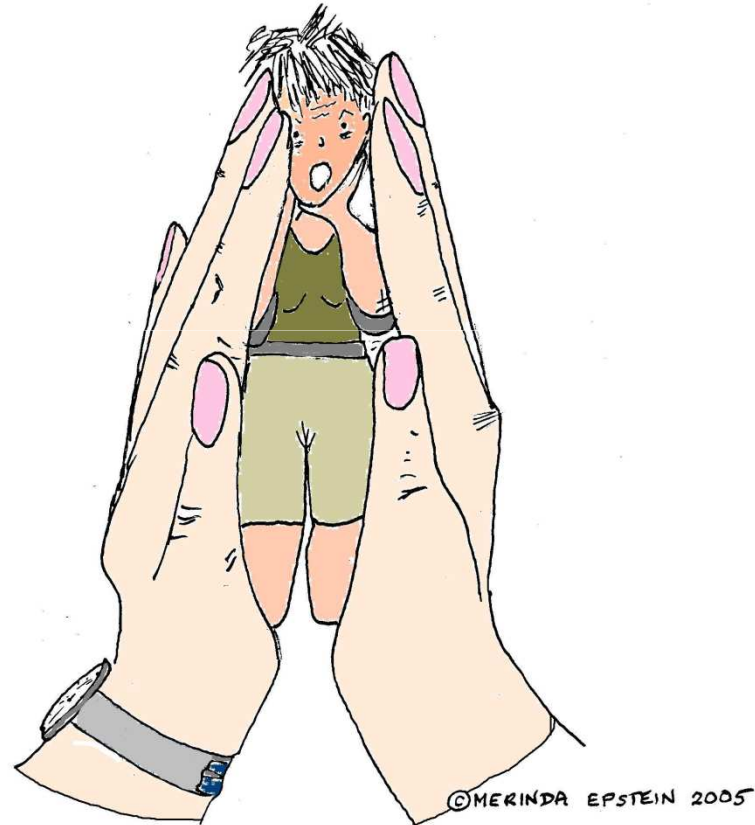
PATHWAY ONE– road to greater happiness and hope through acceptance

- 1. Accept that ‘the problem’ lies in us;**
- 2. Want to learn new practical skills;**
- 3. Find very strong, clear boundaries essential.
Grateful for them later;**
- 4. Search for a therapeutic relationship that is
predictable;**
- 5. Concentrate on finding ways to make
everyday life bearable;**
- 6. Sometimes believe that the early trauma is
too difficult to tackle.**

The nub is acceptance – of our lives (past and present) and of others in our lives -

1. Acceptance of dominant therapy typologies might be psychotherapy or behavioural – or both.
2. In searching for acceptance we often feel ashamed of who and what we are/were. Shame often drives service seeking.
3. Often searching for our lost self respect.
4. We often respond to therapy that holds 'HOPE' for us.
5. This path takes us towards finding acceptance of the things that happened a long time ago and we can't change now.

FITNESS TO PLEAD



PATHWAY TWO– road to greater happiness and hope through fighting back

- 1. Accepts that the problem lies squarely in society**
- 2. Respond to approaches to therapy which consider the political dimensions of distress;**
- 3. Respond to therapies that appreciate that being angry is fair cop if you've been treated badly by society in the past;**
- 4. Seek treatment for the results of previous iatrogenic practice;**
- 5. Believe in therapists who believe them about their childhood trauma and work primarily with this aspect of their distress;**

The nub is resistance – health through strength and not accepting what is wrong

1. **Strongly attracted to consumer-run alternatives to traditional services – responses that recognise the importance of power and the potential problems of any relationships where unequal power is an issue.**
2. **See 'Borderline' as a feminist issue and respond to feminist therapies;**
3. **Sometimes respond less well to 'behavioural' type therapies which often feel demeaning and disrespectful of the pain – both present and past;**
4. **See therapists as having to prove themselves;**
5. **Empowered by non-acceptance of the things that are wrong with society.**



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SEE THE HARM → FEEL THE HARM → SHARE THE HURT → GOING FORWARD TOGETHER

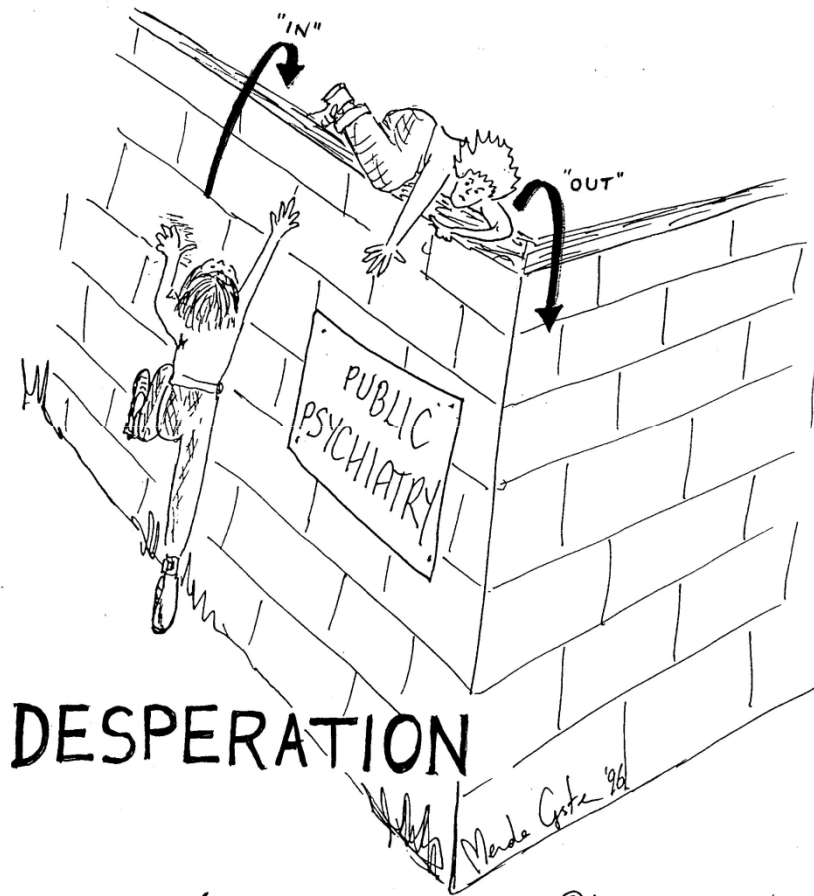
TRAUMA INFORMED PEER SUPPORT

CONUNDRUMS

- From reading a lot of material written by consumers and by observing the system myself and talking to friends 8 really obvious contradictions and questions seem central to many of us diagnosed with Borderline:
 1. **Discourse of management (of patients) versus a discourse of responsibility (for ones own life)! How can this work?**
 2. **Discourse of 'hope' versus a reality for many of us of being treated as 'hopeless'. .. discourse running ahead of itself?**
 3. **Educating yourself by reading '*the literature*' or popular books and material (many aimed at the 'carer' market) versus being totally defeated and destroyed by the language and ideas found in this material.**
 4. **Being invisible and neglected versus being visible in ways that bring harmful interactions with the 'helping' professions.**

CONUNDRUMS

1. **Accept pathologising our 'souls', our inner most beings, our personalities (so different from an 'illness' really) and get services (perhaps) or resist medical imperialism and get nothing.**
2. **Fight to call 'Borderline' a 'serious mental illness' and the status (and ? Services) this may bring us versus the increased risks of medical drugs being forced on us and being imprisoned under the Mental Health Act.**
3. **Demanding that the system has a 'duty of care' for our health and welfare versus potentially loosing the 'dignity of risk'.**
4. **Doing it ourselves collectively or desperately seeking services which might do harm**



DESPERATION

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Language, is the tool we use to think therefore it is critical...

- 'The borderline/The borderline personality'
- **'They, them, those (othering)'**
- 'The narcissist/The narcissist Personality'
- 'Splitting'
- 'Difficult cohort of females'
- 'Co-dependent' / 'Enmeshed'
- 'Slashers'
- **'Mini suicidal gesture'**
- 'Acting out attempts'
- **'Manipulative' / 'attention seeking'**
- 'Non-socially sanctioned self harm'
- Unconscious non-compliance
- **These females..**
- This population of clients
- Working with this population
- Managing this client
- Managing these clients
- Therapy-Interfering behaviours
- Other clinical populations
- **Perception of abandonment**
- The suicidal patient
- Termination of therapy
- Caught committing deliberate self harm'
- **'para-suicidal events'**
- **'difficulty engaging properly with the therapist**
- treatment resistant condition

CASE STUDY – Accident & Emergency (A&E)

1. **National Institute for Health and Clinical Excellence (NICE)** – The National Clinical Practice Guidelines – Self Harm: Britain 2004
2. **NICE REPORT** called for a national education program for A&E staff around dealing with and providing adequate, non-judgemental service for people who self-harm; calling for people to be treated with respect and reporting that things were really crook in A&E Departments universally
3. **CUT IT OUT, PLEASE;** Rachael James (pseudonym), an Accident and Emergency Clinician wrote a scathing letter to the Guardian newspaper berating the report and its authors. It's a very angry letter that has a go at all of us who self harm and although her purpose is to argue that education should be aimed elsewhere (not at A&E staff) the intemperance of the language and much of the content of her letter belies this argument.
4. Rachael James' letter can be found on the link below:
<http://www.guardian.co.uk/lifeandstyle/2004/aug/03/healthandwellbeing.socialcare>

Some of the language used in Rachael James' public letter to the Guardian

1. **People who self harm are:** “wilfully immature”; “displace more needy patients”, and “seem to thrive on the chaos they cause and attention they receive.”
2. “It is hard not to get frustrated: people who self-harm do have a choice, although it may not seem like it at the time. They could not do it, or they could do it and stay at home to deal with the consequences. Just please don't lacerate yourself, come to hospital and then complain about it!”
3. “Self-harmers who attend hospital habitually are unable to take responsibility for their own lives and actions, and it might be that by being so patient and non-judgmental we are fostering that destructive cycle.”

Quote from practising psychiatrist

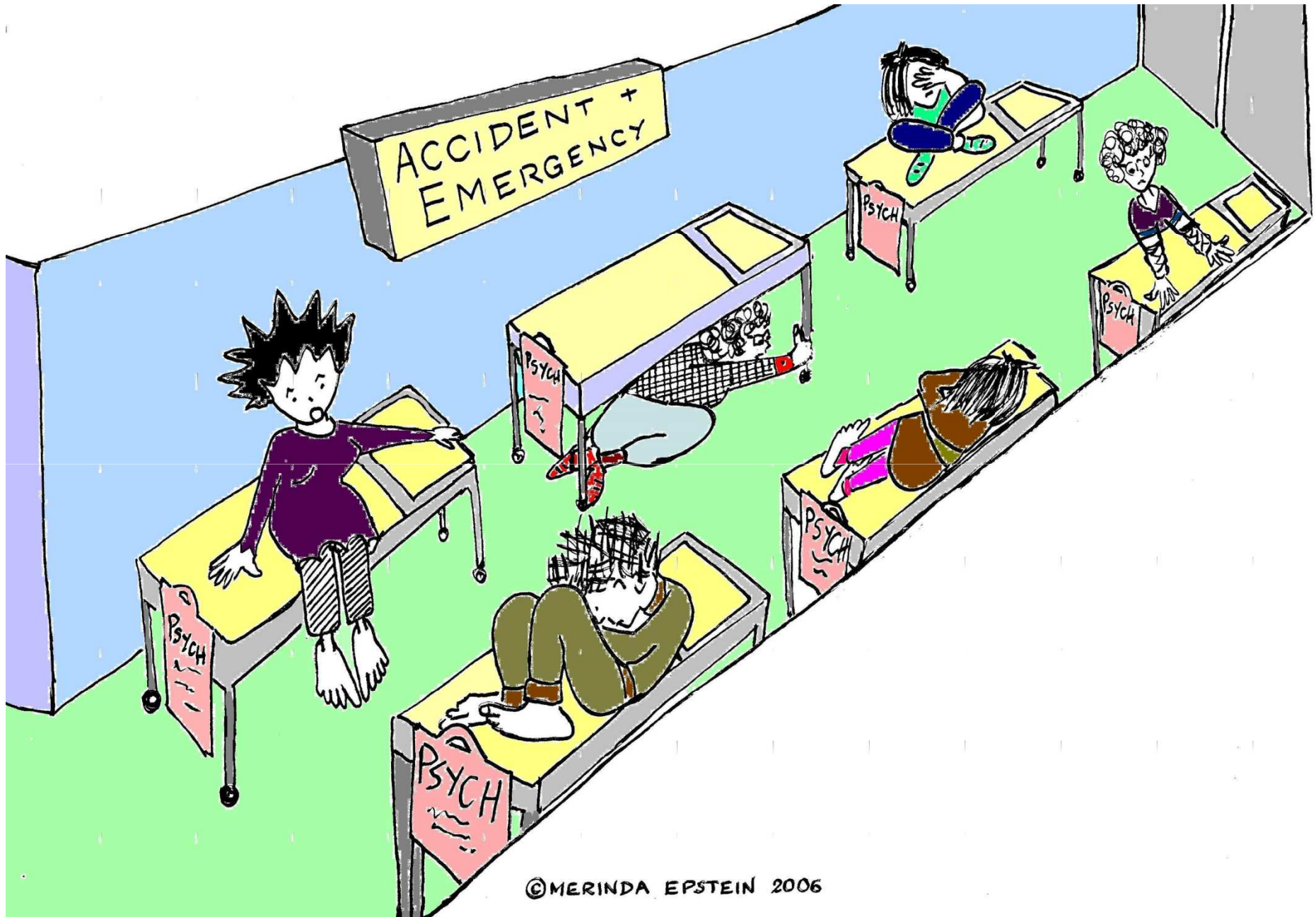
- “I think she [Rachael James] speaks for many of us who have spent years dealing with these people and, from a psychiatric point of view, getting metaphorically pissed upon by those serial offenders who are not even mentally ill”

Responses to Dr. James from Doctors

1. More than 50 responses from Drs. on psychminded.co.uk
See
2. <http://www.psychminded.co.uk/news/news2004/august04/Psychiatrists%20criticise%20colleagues%20who%20describe%20self%20harming%20patients%20as%20wilfully%20immature.htm>
3. It makes fascinating reading: Many agreed with Dr James
4. Several demanded that patients who self harm should be made to pay for their use of A&E services or have these costs deducted automatically from their benefits. This is in a country where health for everyone else is free.
5. There were other doctors who were alarmed by these comments coming from their colleagues. See:
http://thestressoflife.com/psychiatrists_rebuke_colleagues_.htm

The Bill of Rights for Those Who Self harm

- 1. The Right to caring, humane medical treatment.**
- 2. The right to participate fully in decisions about emergency psychiatric treatment (so long as no one's life is in immediate danger).**
- 3. The right to body privacy.**
- 4. The right to disclose to whom they choose only what they choose.**
- 5. The right to choose what coping mechanisms they will use.**
- 6. The right to have care providers who do not allow their feelings about self injury to distort their therapy.**
- 7. The right to have the role Self-Injury has played as a coping mechanism validated.**
- 8. The right not to be automatically considered a dangerous person simply because of self-inflicted injury.**
- 9. The right to have self-injury regarded as an attempt to communicate, not manipulate.**



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STIGMA in SERVICES

- **“A new kind of stigma has emerged within mental health. It relates to legitimacy: ‘the mark of infamy’ is not now that of being ‘mad’ but rather of not being ‘mad’.**
- (Olsen in Meadows and Singh, Mental Illness In Australia 2004 p.19)

Degree of Oppression

- 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.
- From Magazine for Democratic Psychiatry, 2004

	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				