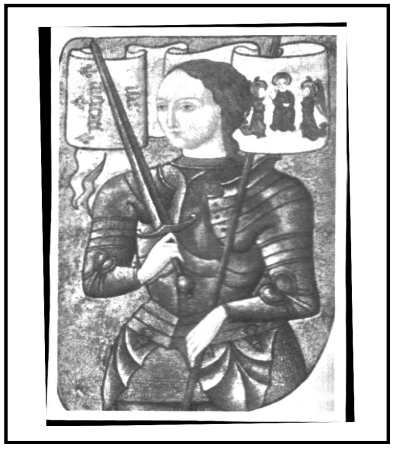
SPECIAL ISSUE:

ExtraOrdinary People



News from the Joan of Arc Project July – September 2005

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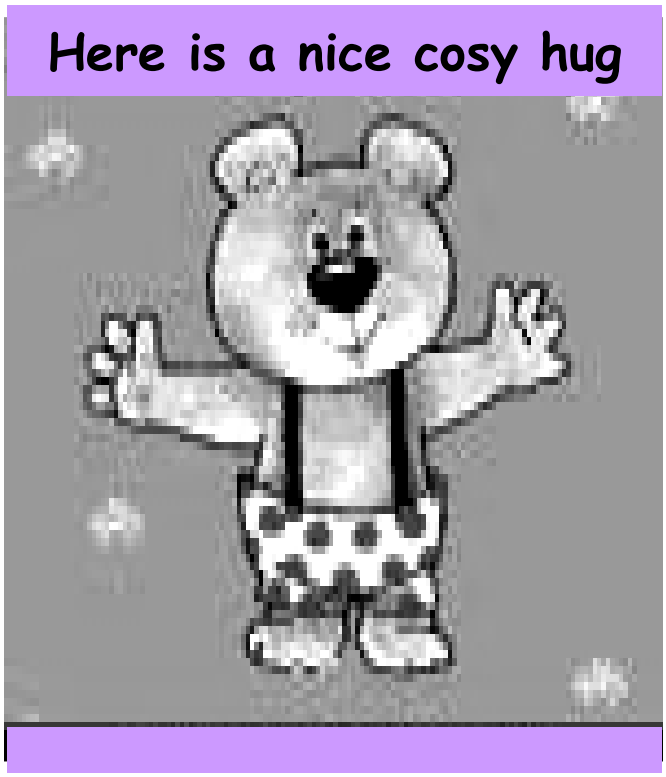
Editorial:

The Joan of Arc Project embraces causes of many different types, some with funding, others without. One that is supported (by NIHME) is that of setting up a self-help network in the South-West for people who have been given the label of 'Personality Disorder'. These "ExtraOrdinary People" feature in this Special Issue of the Joan of Arc Project Newsletter. The articles featured were written by people affected in different ways by personality disorder. Read together, I hope, they represent a broad spectrum of some of the emotive issues on the topic as well as providing some real hope for sufferers.

Full name of authors and further copies are available on request.

More general Joan of Arc Project information in brief may be found at the back of the newsletter.



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when
there's nothing left to live
for. where do you turn
when you have nothing
inside to give to the world

borderline rhyme?
It's about time
someone cut the rope
and let me fall
fall
fall

there's nothing left at all
to live for

Anna

In Other Words …

Why don't you UNDERMINE your DIAGNOSIS - you do know what your diagnosis is, don't you? (because I know it and it means I can have control over your psyche with it in my hands (and words)).
You can go to a psychotherapist specialising in taking the Personality Disorder out of the Borderline (vis-à-vis psychiatric, manual, unstable, erratic, attention-seeking, victim).
Why don't you undermine your diagnosis?
Why don't you rewrite your history? … (hang on mate …)
Whose life is it anyway?
I'm face-to-face with a LANGUAGE BARRIER - words fail me …
But in language I am re-born.
Doesn't it occur to you that my SURVIVAL was the writing of my own story: clinging onto a present; avoiding a future; running from an ever-present PAST.
You suggest asking a psychotherapist to write off my diagnosis (a.k.a with therapy that little nuisance of your 'disordered personality' could be cured!).
I wait - your arrogance leaves me in astounded shock … (short delay …)
and then … wait a minute Mr CPN, sir: you're saying get the therapist to de-label me? Is that the gist of it?
How empowering?
But you seem to forget that while I was being destroyed by their psychiatric definitions and their psychiatric arrogance … while I was being controlled and restrained and dragged down stairs hard against my body, while I was screaming out my humanness to a room filled with blank faces eager to dehumanise me; to define me; to rob me of my dignity - well then I <u>was</u> writing - I was writing my own story - to SURVIVE - to try to stay alive!
I existed before I was stamped with a psychiatric label and I still <u>am</u> even with its imprint upon my skin.

I cannot erase my suffering. I chose my own words for a change. But it means a lot to me because it explains something of where I have been and how I am where I am.

Anna

The Mysterious World of the PERSONALITY DISORDER

Given that the human being is (full evidence base) a complex, extremely sensitive and emotionally delicate being, we should not carry on behaving so negatively (risk) towards the ever-increasing number of us who experience extremes of ill-health when this delicate emotional being is knocked off balance.

The human being has its own inbuilt self-preservation survival tactics or mechanisms ingrained on a deep genetic level into each and every one of us. Should we really be punishing people or not helping them or writing them off (labels) or seeing them only as a 'risk' or a 'cost' when they are really only acting 'normally' to extremely traumatic or life-threatening experiences which will or have shaped their lives if they didn't receive help at the time? Does this make these people criminals or misfits or risks? NO, it should not! Does that give the rest of us the right to use these vulnerable and sensitive and ill people as a dumping and testing ground for all classes of strange and widely unproven chemical drugs (with side-effects) - for *profit*? In the name of what, I would ask - 'caring', 'curing', 'medicine', 'recovery', 'helping', etc.? What about addressing the root of the problem?

The stigma that goes along with these 'diagnostic labels' is enough in itself to create more illness. The labels themselves are inadequate to measure the 'Human Being' with any accuracy both for today and for the future. The stigma has largely been whipped up to a risk level by scare / fear tactics and the media and is spawned out of ignorance and fear. This is WRONG from a human viewpoint and taken together makes for a dangerous 'cocktail'.

Human beings always need emotional nurturing even in non-traumatic times. When they don't receive this at times of dire need then the person may go out of balance. A person who is out of balance does not react or behave in a way that matches with the very narrow view of society's 'norm' in a diagnostic sense. It appears to be these behaviours and reactions and beliefs that when ongoing, justify or merit these labels or diagnoses of Personality Disorder. But where does all this RISK come from, I again ask? I still feel that a person is made up of the PHYSICAL, EMOTIONAL, MENTAL and SPIRITUAL.

Any of these parts can easily go out of balance and this will undoubtedly have a knock-on effect on the others unless the cause is addressed. It shouldn't take genius to work this out - it's simple!

It can take a long time for a person to become emotionally out of balance; I believe that it will, in many cases, take plenty of time, care, love, support and help for this delicate balance to be regained (recovery). So, for my part, I cannot see what the problem really is in helping people who are emotionally out of balance to recover to a level where this Personality Disorder label isn't their end station in life. This is a 'society problem'. It is no good being in denial of the fact that humans are very sensitive, delicate and complex beings - this denial will only lead more people into illness - Personality Disorder - which potentially lies at the very heart of each and every one of us. If so, then just where is the mystery world of Personality Disorder? I believe we should focus more on recognising and responding to emotional negligence / ignorance and help make Personality Disorder a 'label' of the past?

The Trouble with 'Labels & Boxes'

The problem with the current Personality Disorder (PD) labelling system, the DSM / ICDS, is that the labels are square, negative, rigid, inflexible and limited boxes. But people (humans) are definitely not. I have never met or even heard of a person with ONLY negative personality traits. Nonetheless, we are being forced and bullied into these uncompromising boxes / labels / diagnoses regardless of whether there is an individual way forward / recovery once we have been inflexibly categorised or not. When you add the stigma and the huge lack of understanding to this extremely limited and frightening list of negative personality traits, it makes for a dangerous and tortuous and limited life for the patient as well as for their carers, families, children, friends, loved ones, clinicians, support staff who all also suffer because of it.

Under the current system the illness is being compounded in a great many cases by the lack of understanding from most people who haven't experienced the illness themselves. This lack of understanding plainly invites more illness often drug and / or alcohol abuse (legal and illegal), suicides, self-harm, criminality, anti-social behaviour, the destruction of families and emotional desperation.

This is the start of what is called 'Revolving Door Patients' or in plain English, hopelessness itself.

I am convinced, after much research, that these PD labels are a futile attempt to categorise on paper the individual human traits of a person from a negative-only viewpoint. Call this a Personality Disorder if you will! I thought we are all individuals with our own genetic make-up; with our own individual traits and life experiences. But under this system of diagnosis, this appears not to be the case; i.e. are all depressed people suffering from PD or do all people with PD suffer from depression? Is everyone who presents road-rage or any angry behaviour all suffering from PD? Are all our prisoners or criminals suffering from PD? Are all suicide or self-harm cases PD related? Or drug and alcohol abusers? Has everyone who has ever suffered because of rape, child-abuse, bullying, mental, physical, emotional abuse got PD?

But . . . a great many of us have suffered from some or all of these things . . . and a large number of us have and still are being diagnosed with this 'thing' called PD. When one does have this illness, 'survival' becomes the key factor. This often leads sufferers in a negative direction as it is the easiest or sometimes only option open to them. Sufferers who ask for help are forced to go the same route as people who may have got the label via the Criminal Justice System - criminalising illness - is this the right way to go?

RISK, RISK, RISK - but no consideration / allowance for the fact that a large proportion of the people being diagnosed are on mind-altering drugs (legal and/or illegal), alcohol, etc. and presenting with 'unusual' behaviours. Do you not think that you would also 'suffer' under this system if you were ever unfortunate enough to develop this illness and ask for help? I can assure you that a large number of you out there who don't have this condition would also fit into these 'Personality-Disordered-Boxes' if subjected to this very shallow and limited diagnostic procedure.

Once you have been given the label then more trouble starts. No information that makes any sense, practically no effective treatments so far, no-one to talk about it, not being taken seriously anymore without a battle, everything just put down to or dismissed as a 'symptom of your illness'. You get the reputation of often being aggressive or abusive even when you aren't.

And to top it off, you are now actively persuaded or even bullied to take a lot of mind-altering drugs - maybe even for the rest of your life! But do they make you better or cured or maybe just more confused? And now drugged - with side-effects to boot! These drugs do alter behaviours and thinking but we just don't know enough about them and how they affect each individual to be able to distinguish anymore what is behaviour 'normal' to the client or what part is illness or what is drug effect or a mix of all of these? But STILL this diagnostic procedure carries on regardless. So once again, I say RISK, RISK, RISK but to the client / sufferer in this case; unfortunately this gets ignored too.

So, overall it is a pretty grim picture for sufferers of PD up until now. I personally would give all the people currently with the diagnosis a medal for courage in the face of extreme adversity. On a more positive note though, there does APPEAR to be a good deal of work being done in and around Personality Disorder and its effective treatment both locally and nationally.

So, all I can say is: - "Watch that space - don't despair - and HOPE . . . for our futures.

David

Personality Disorder

Just words? No, it's a label that feels as if you're being told that who you are is all wrong. Joe Public thinks you are probably some of mad axeman and that you should be locked up. Physical ailment doctors and nurses treat you as if you are neurotic or simple. The government say personality disorder is not a mental illness. That being the case, why are sufferers sectioned and given antipsychotic drugs? To the courts, police, A&E staff, and probation services, to name but a few, you are mentally ill.

In the dictionary, the word 'personality' is defined as the 'enduring pattern of thoughts, feelings and outward behaviour which makes each of us individual. We tend to react in a similar way and our behaviour changes to adapt to each new challenge we face, drawing on our past experiences and behaviours.

The DSM lists ten personality disorders each with different symptoms, ranging from social anxiety, self-harm and paranoia to inadequacy, perfectionism and disregard of other people.

Through the ExtraOrdinary People Project, you discover that you are not alone with your label. Being able to talk about your so-called disorder and your life experiences without being judged, helps to lift the burden and you don't feel so stigmatised. One thing that came out of the training day was that even 'normal' people could say they had some of the 'symptoms shown on the T-shirts showing the DSM definitions. So, are those of us labelled with 'personality disorder' just individuals whose life experiences have made us less able to cope in the modern day world?

As ExtraOrdinary People progresses, it is hoped that we can set up self-help groups (well, psychiatry doesn't have the answer) and educate the 'establishment' letting them know what it is really like to have a 'personality disorder' and what you need to improve your day-to-day life.

Kate

Some thoughts about personality disorder and distress

I work as the manager of an open access mental health resource centre in Plymouth. I have worked with a number of people who have been diagnosed as having personality disorders. These are some thoughts about the label – ask me on another day and I might think something else.

Kate the Great, easily the best laughter therapist I have seen, used to tell the story of her progress as a mentally ill person. She said that when she was first ill she was diagnosed as having schizo-phrenia, and given medicine with bad side effects which made her feel awful. The medicine didn’t work so she was diagnosed with manic depression and given some different medicine, also with nasty side effects which made her feel worse. When that didn’t work she was told she had a personality disorder – so she wasn’t given any more medicine and she started to feel better.

Sadly many people with personality disorder diagnoses don't end up feeling much better. The personality disorder diagnosis is often used as a way to deny help – and to dismiss distress. The diagnosis is often coupled with the adjective incurable – and of course no one has to try to help someone who is incurable. This is why it is sometimes referred to as a "dustbin" diagnosis.

People often experience distress that has no obvious immediate cause. When this happens it is often seen as illness or as a sign of illness. For example, someone faced with an obviously real life-threatening danger might be described as anxious but someone experiencing the same symptoms in situations that most people find unthreatening is described as "suffering from anxiety".

Mental health professionals often see distress in terms of the existence or absence of named "illnesses" – people who hear persecutory voices have schizophrenia; people who experience periods of elation alternating with severe depression have manic depression, and so on. These names are really only coded descriptions of the patterns of distress people perceive – none of these "illnesses" are detectable by clearly measurable physical signs like measles or flu.

People who get diagnosed with personality disorders are often people who experience and express distress in ways other people find unacceptable, such as by self-harm, and who, don't respond to the normal drugs in the required way. Sadly instead of working with such people to find ways of helping them cope with their distress mental health professionals too often cover up the difficulties and distress they themselves face in this challenge to their competence by using the diagnosis as a reason to deny help.

It might be better therefore to develop services that respond to the distress that people experience without the need to label them, and which attempt to deal with real needs with flexible support rather than with standardised prescriptions.

Joe (H)

East Devon ExtraOrdinary People's Group

I am a Project Worker out in East Devon and my position is very much a learning and listening experience and I feel privileged (for want of a better word) to be part of people's sharing. This only goes to strengthen my belief in seeing and hearing the person behind any judgement I may be holding which all of us I think can make through our own prejudices not withstanding mental health issues.

Working in Mind for me is about being around people and perhaps naively labels have never been an issue because there aren't any except for the fact I am the one who loses everything and sometimes doesn't know what day of the week it is. Acceptance in Mind is for me what makes it a safe respectful place to be in.

The East Devon Group has been meeting for about four months and is still very much in its infancy. The next meeting is Tuesday 19 July at 11.00 am at The Haven in Honiton. These meetings are facilitated by Elaine from Exeter who is the inspiration behind the ExtraOrdinary People and hopefully in the future people from East Devon can meet up with the Exeter Group and the other groups in the Region. One thing I would like to mention is that because we cover a large area the organisation of regional meetings takes times due to the planning of lifts not only to the venue but from where people live. So if anyone out there in the ExtraOrdinary world would like to invite us out please allow two or three weeks for this to be arranged.

It is really great that the opportunity has come along through the work of Elaine, Andrew and Clare from the Joan of Arc Room to create a group out in East Devon where people can feel safe to share whatever comes up for them without the fear of being judged. I have just had an idea what about a 'joint shaking off the label disco'?

To end I'd like to share something which was said in the group which I don't feel is breaking confidentiality - "I don't want you to do anything about what is going on for me I just would like a hug." This struck me very deeply - the touch of listening!

Trudy

A Personal Experience of Self-Harm

How do I describe what seems indescribable? How can I describe the beauty of watching my blood flow? How do I describe the ecstasy of stubbing out a cigarette on my skin? How can I explain the perfect calm which comes over me after I hurt myself? Such a strange kind of comfort.

Our primary instinct as human beings is meant to be that of survival. Deliberately mutilating oneself seems completely opposed to that instinct. But in actual fact, it is about survival. I don't self-harm to kill myself (although there is always a certain recklessness, a tempting of fate): I do it to stay alive.

When my emotions become unbearable, when I feel like my head is going to explode, I write my pain on my body. I transform the invisible scars inside into physical wounds. I cry with tears of blood, showing myself how much I am hurting, so very badly. I am hurting so very badly. I don't do it to manipulate anyone. It's to put the inner pain on the outside; to make it somehow more manageable. What I do hate and feel guilty about is the way I lie to those who care about me - I tell them that I'm fine and then I go off and hurt myself. I can be so sneaky and devious, just like any addict desperate for their fix. And it is desperation. A desire and a need so strong that it's like I'm drowning, pulled under by a black wave. I feel possessed by something other than myself, powerless to resist. Images of self-inflicted violence fill my mind, like a terrible film that I am forced to watch over and over again.

Afterwards, I beat myself up for being weak. Maybe I could fight harder but the second I give in, see my own blood flow, it's an incredible release and relief. I am transformed, I stop shaking, and I feel calm, clear, light; and almost happy?

Every time I hurt myself, I want it to be the last time. But the desire always comes back sooner or later: almost immediately if the injuries I inflicted weren't serious enough to require medical treatment. I seem to need a certain level of severity in order to be satisfied. Last year, whilst dressing the hand I was burning repeatedly (on top of a skin graft), a nice nurse said to me: "… You'll be down to the bone soon." How can I possibly describe

the secret rush of elation, the excitement and yes, the happiness that came over me at the thought of it? Does that sound so sick? But I was obsessed with the idea. It's like I want to see inside my body, dissect it, and get under the skin. Strip it down, in search of some core of blackness and badness I am sure lives inside of me.

Because self-harm is also about punishing myself: blaming myself for my life; blaming myself for being worthless and ugly; blaming myself even for breathing. I hate myself and I assume everyone else does too.

I find this article hard to write because self-harm is so complex. Need and desire; desire and need are truly but tricks of the light; they blur into one, they confuse me. Survival, addiction, comfort, punishment; there is no one simple explanation or reason. As a kind doctor once said to me at the Casualty Department one night - if he knew the key to it he would tell me. But I am just left struggling and often despairing.

I began this piece with questions, and I will leave it in the same way. Will there ever come a time when I can let go of this crutch, this way of coping I have used for so long? If so, will it be a moment's revelation? A gradual dawning? Will I ever be able to look at knives, scissors, razors, broken crockery and, even cigarettes without seeing objects of love and desire?

Ros

Growing Pains?

Hi, I would like to explain where I am and how I got here:

Well, I am at school in Orchard Lodge - a young people's unit i.e. a nut-house. My story starts like this … I was at school (West Exe Technology College) when I heard a man calling my name; I looked around but saw that everyone had their heads down and were working hard. I just ignored the incident and carried on my 'normal' life. A couple of weeks later though, on a Friday night, my mates and I were out on the 'razzle' and I went too far and ended up in A&E. But before going to the hospital I saw this dead girl hanging and the same man

I'd heard before saying that she was going to touch me on the shoulder. I didn't know what the hell was going on and I thought that to tell any of my friends would be madness - they would all call me totally nuts for sure.

Some Fridays later it was becoming too much and I got pissed again and I decided that I couldn't handle this anymore. I found a bridge and I was about to jump when I heard my friends shouting at me to come down; the voices on the other hand, were encouraging me to jump to be like the dead girl hanging. The police were called and eventually brought me down. The police kept me in a cell for 16 fucking hours until I was assessed to see if I needed to go into a nut-house. They told me that they didn't think I needed to go in but then they didn't know that I was hearing voices. They call themselves 'professionals' but if this were true, then surely they would have been aware of and picked up upon my voices? Anyway, I told them that I would rather kill myself than go home but when presented with a choice between home and a foster home, I opted for the former.

A few Fridays later I decided on another way to 'end it all' - by using 3 litres of cider and a tab and a half of E. It seemed to work … I was out and I thought I'd gone … until I woke up in hospital with an oxygen mask, a drip and a blood pressure machine (going ping?). I can remember thinking … 'for fuck's sake God, why won't you let me die?' And so I went through the same routine of being assessed again and of being packed off back home. It felt to me as if I had screamed to them for help but they either couldn't or didn't want to hear it. They offered me family therapy and a CPN. I tried to work with these 'professionals' but after a month or so of working with the CPN I told him that I was hearing voices. He told me that I was not mad - I thought to myself - if I am not mad then what the fuck is?

Friday evenings seem to come and go but by now the voices were becoming unbearable. I'm only 15 years old and I couldn't hack it - I threatened to jump off the bridge and I cut my wrists. My dad rang the police and they found me and said I should go to A&E to get my arms checked out. I went to the hospital and I flipped and couldn't handle it - a psychiatric doctor came and said that I should go to a hospital in Exeter called Larkby.

I was there for 6 months then had to be moved on because I was too bad to handle. From there, I went to Orchard Lodge in Taunton, Somerset. Hopefully, I will be off my Section 3 and be discharged a.s.a.p. so that when this article is read, I will be out after nearly a whole year. I am 16 now and I have spent my birthday and Christmas in Orchard Lodge.

I am glad that I've shared my experiences with you and hope that it may help in some way.

Lucy

Ages and ages . . .

. . . nine, ten, eleven: care-free, strong willed, independent, didn't ever question happy or sad - just got on with being a child.

. . . twelve, thirteen, fourteen: discovered what it was like to be bullied. Felt the pain and salty tears of fear. Learnt to hurt alone. Learnt my family couldn't take my hurt away. Aspirin - people take them for aches and pains. I took them for my pain but they didn't work very well - they did the opposite - I felt disgusted, ashamed and physically pained as my dad watched me vomit; my mum watched her fourteen year old daughter's stomach being pumped out.

The pain never went away. I went out with friends, took exams, went to college. I smiled, I was polite, hard-working and seventeen.

I was admitted to hospital for 14 months and I hurt like I'd never hurt before. 'Severe depression', the doctor wrote. Is that my experience summed up in two words? I felt humiliated, put down, made small. My body was made fat and bloated by the drugs which I pleaded day after day, night after night, not to be given. I cried tear of hopelessness. Often fear froze me to the spot for hours on end.

I reached eighteen, then nineteen and twenty. I moved from hospital to the Richmond Fellowship, then onto my own flat and I got a job. Behind closed doors, my life was spent vomiting up to

40 times a day and taking large amounts of laxatives. My arms were scarred; my body exhausted. Childhood dreams dramatically snatched from me. Now fighting for survival, I was killing myself.

. . . twenty-one, twenty-two, twenty-three, twenty-four: marriage, children, bulimia, depression, anorexia, alcoholism, treatment centre, hospitals, children in emotional pain, overdoses, cutting. Nothing. Nothing to feel, nothing to think, for feeling and thinking hurt too much.

. . . thirty-three: divorce comes through. I can stand on the top of the mountain and admire the view. My stomach knows what it is like for food to sit in it and I am the proud owner of 'normal' poos! Thirty-four, I go to college, get accepted at university and start a

degree. I beat myself up for doing so well. Cutting after an eighteen year break. Hearing voices, overdoses, visions, arrests, sections, fear running through my veins, children in upheaval. My body dressed in guilt and shame.

Labels for me - designer ones I'm sure - straight from the DSMIV: psychosis; personality disorder; borderline schizo-something; obsessive-compulsive personality disorder unspecified are a few; 'manipulative and attention-seeking' didn't suit me too well. 'Theatrical' would have been nice if I was a drama student: but I'd just spent 16 hours in a police cell.

Today, I wear different labels - Marks & Spencer, Gap. Etc., and when I talk of jeans there is nothing medical about them at all. The only thing that runs in my 'genes' is a pair of ….. not too unsightly legs!

Elaine

ExtraOrdinary Drama?

Following the ExtraOrdinary People day in Exeter last summer, a number of people expressed an interest in forming a group to explore ideas and feelings through the medium of drama. Having just completed an MA degree in Applied Drama, and having an interest in mental health, I was happy to facilitate this.

We began to meet at the Joan of Arc room on a fortnightly basis, and continued to do so over about six months.

Considering we were looking at a pretty hard and complex topic, it's surprising that my over-riding memory is of the amount of anarchy and laughter that we shared. Our drama wasn't 'therapy', and was always a response to what people wanted to explore. One day, for example, we looked at labelling, and made it into a physical exercise that completely overwhelmed the recipient of the labels; a very visual demonstration of how it felt to be in that position. On another occasion we assessed status, using a theme of a ward with the patient as the starting point. We added ourselves, one by one, to make a group picture with each person making themselves appear higher in status than the one preceding them. The result gave us enormous amounts to consider in terms of body language, of people, arrangements of rooms, relative heights of people in the scene. We spent some time analysing this against personal experience. We had some fun simply playing …. we explored the theme of silent movies...but stopped short of translating the genre into a psychiatric setting: so who'd you choose for your villain..!?

Our aim, I guess, was to enjoy the opportunity of exploring and playing with ideas. Although we framed each session with song and warm-up games (remember the multi-coloured safety rope, guys?), we then followed our noses for the direction of the session. I think drama is an excellent medium to use because group members can dictate the intensity of the sessions. We looked at some difficult situations, always observed confidentiality, and only went as far as we were comfortable with. As well as all this, when we just wanted to have a laugh, do something purely for the sake of it, we did just that! I think we all relished the idea of playing - of not having to demonstrate a worthy result - of just having fun!! The sessions wound to a close with a focus towards a training day in Exeter. I hope in this short piece I've summed up accurately and presented a view that those involved in the group would agree with (especially as I haven't had chance to request their permission).

Julie

A view on Borderline Personality Disorder: Whose Borderline is it?

Perhaps no diagnosis carries a greater stigma than “Personality Disorder”. Untreatability. Those with personality disorder have been described as “the patients psychiatrists dislike”, or to be made to feel like time-wasters, not-treatable, manipulative, bed-wasters or attention-seeking; terms that people with this diagnosis have actually reported being said to them. But what does the term ‘borderline personality disorder (BPD) really mean? And if there is such a thing, can it be helped?

Psychiatrists describe borderline personality disorder as a serious mental illness, characterized by pervasive instability in moods, interpersonal relationships, self-image, and behavior. The sort of symptoms that this refers to includes; an intense fear of being alone; a very uncertain shaky self-image; impulsive behaviour such as extravagant spending or binge-eating; extreme mood swings; terrible feelings of emptiness; intense anger that’s difficult to control; and periods of paranoia. These can lead to instability, often disrupting family and work life. Many of these are very common experiences that express a range of difficulties and problems, and are far from unique to BPD.

Originally thought to be at the "borderline" between psychosis and neurosis, people with BPD are said to be suffering from a disorder of emotion regulation. While less well-known than many other mental health problems BPD is quite common, affecting two percent of adults, mostly young women. There can be a high rate of self harm as well as a significant rate of suicide attempts and completed suicide in severe cases.

The distinction made between "normal" and "disordered" personalities is itself a difficult one to justify or prove. The judgment as to whether a behavioural pattern is normal or disordered is also highly subjective. MIND, for example, does not accept that a diagnosis of personality disorder is always accurately applied. It may, for example, be used to label behaviour which is simply difficult and different. In fact MIND has been very critical of the label as a ‘dustbin diagnosis’. Cultural and gender bias is evident. In one study, for example over 80% of people diagnosed with BPD were women. Also, these women had had very troubled lives, with significant traumas to contend with, 81% had histories of major trauma, 68% had been sexually abused, 71% had been physically abused, 62% had witnessed severe domestic violence.

This suggests to many, a very close connection between very adverse life circumstances in childhood and the likelihood of attracting a BPD diagnosis in later life. The issues this observation raises are very real, regardless of what we might think about BPD and whether this is a genuine 'illness' or even a helpful description. It is also very clear that most people's actual experience of mental health services across the country has been deeply unsatisfactory.

In several user-based surveys, by NIHME and others, these are the sort of things that service-users say:

'There was strong agreement that there are not enough services available for people with personality disorder. Everyone in the groups had experience of general mental health services, and the majority were negative. They reported widespread unhelpful attitudes from staff, who would see them "as just the label", and were often prejudiced about their condition, and belittling or patronising in manner'

They also had some very clear ideas about what works, and what would be better.

"*Specific services for PD are helpful – but general mental health services are not helpful and can be abusive*."

Early intervention was highlighted as crucial to the prevention of major deterioration in personality disorder. The need for specific services covering an age range of about 15 -25 was suggested.

"Had I been helped when younger I would not have got this bad."

There needs to be acknowledgement by professionals that personality disorder is treatable: a negative experience initially makes engagement less likely. There was also general agreement that endings of therapeutic relationships were often not addressed adequately. Also, once people show any improvement, services can be removed; this can discourage improvement.

"There is a link between hurting yourself and getting support and treatment. It is hard to resist self- harming behaviour when, you know if you do it, you will get treatment."

Choice of treatment was felt to be important: if involved in deciding about their treatment, patients are much more likely to co-operate and engage successfully.

If there is no choice, and people don't take up the treatment they are offered, they are often labelled as non-compliant. It was also felt that different treatments work best for different people. Specific treatments mentioned were Dialectical Behaviour Therapy (DBT), Cognitive Behaviour Therapy (CBT) and Transactional Analysis (TA), Cognitive Analytic Therapy (CAT) and combination or integrated therapies. Music, art, creative, humanistic, occupational and social therapies were also seen as useful.

'You are told you should feel angry when you don't, and when you do, you're told your acting out"… *"A diagnosis of personality disorder does not mean you're not a nice person."*

I found this summary of all the points that were made very powerful. If mental health services took these principles to heart, there is no doubt that vast improvements could be made.

Helpful features for personality disorder services

Early interventions, before crisis point
Specialist services, not part of general MH
Choice from a range of treatment options
Individually tailored care
Therapeutic optimism & high expectations
Develops patients' skills
Fosters the use of creativity
Respects strengths and weaknesses
Good clear communication
Accepting, reliable, consistent
Clear and negotiated treatment contracts
Focus on education and personal development
Good assessment/treatment link
Conducive environment
Listens to feedback and has strong voice from service users
Supportive peer networks
Shared understanding of boundaries
Appropriate follow-up and continuing care
Involves patients as experts
Attitude of acceptance and sympathy
Atmosphere of "truth and trust"

…can make people feel respected, valued and hopeful

Unhelpful features for personality disorder services

Availability determined by postcode
Office hours only
Lack of continuity of staff
Staff without appropriate training
Treatment decided only by funding/ availability/diagnosis
Inability to fulfil promises made
Critical of expressed needs (e.g. crisis or respite)
Staff only respond to behaviour
Staff not interested in causes of behaviour
Dismissive or pessimistic attitudes
Rigid adherence to a therapeutic model in cases where it becomes unhelpful
Passing on information without knowing a person
Long-term admissions
Use of physical restraint and obtrusive levels of observation
Inappropriate, automatic or forcible use of medication
Withdrawal of contact used as sanction

…can make people into "career psychiatric patients"

Joe

Some service-user perspectives on the diagnosis of Borderline Personality Disorder

The purpose of this research was to explore service-users' experiences and understandings of being given and living with the diagnosis of Borderline Personality Disorder (BPD). 5 people who had been given this diagnosis were interviewed. The interview focussed upon their understandings of the diagnosis and how they perceived it to have affected them, their view of themselves and others' views of them. From these interviews, 5 themes were identified – 'Knowledge as power' (which had both positive and negative aspects to it in relation to the BPD diagnosis); Uncertainty about what the diagnosis meant; Diagnosis as rejection; Diagnosis being about 'not fitting'; and a final theme of 'Hope and the possibility of change'. A consistent aspect of this research was that people valued needs based support and positive relationships.

BPD as a concept has been criticised in terms of its validity as a way of understanding people and their difficulties. Service-User focussed research has highlighted how the experiences of people diagnosed with BPD differ considerably from clinical descriptions (e.g. Miller, 1994; Castillo, 2000) and how the predominant themes in the lives of people with this diagnosis are related to societal and professional responses (Nehls, 1999). This current research is consistent with these findings. It is argued that, for people given this diagnosis, ways of understanding the self which are consistent with a social constructionist perspective are more useful than ways of understanding the self which are consistent with a realist perspective (represented by the BPD diagnosis). Diagnosis was only felt useful when it led to inter-personal and needs-led support. Without this, it was described as rejecting and isolating.

Past research has identified the stigmatising reactions of professionals and society to people with mental health diagnoses. This research suggests that the BPD diagnosis itself can be a part of this stigma, affecting people's views of themselves and being experienced as a stigmatising reaction in and of itself.

Nick

This research was carried out as part of the author's training in Clinical Psychology at Bristol and is currently in the process of submission for publication. The author would like to thank the 5 people who put their time and effort into the interviews reported herein.

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Miller, S. (1994) Borderline personality disorder from the patient's perspective. *Hospital and Community Psychiatry, **45**,* 1215-1219

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Personality Disorder Project Team

In October 2004 the Personality Disorder (PD) Project Team began after funding was successfully obtained from NIMHE SW to undertake a programme of training and development around PD work across the wider health and social care communities. Four part-time Practice Development Workers were appointed from a range of backgrounds together with a part-time assistant psychologist. The team is developing a range of training programmes aimed at increasing awareness, understanding and skills among staff groups across many agencies. This includes primary care, secondary mental health care, voluntary agencies, the criminal justice system and others. The training team employs experts-by-experience to help develop training programmes and deliver them as appropriate.

The training packages under development can be tailored to the specific needs of individuals. Level 1 training consists of awareness raising which provides background information about PD, service-user perspectives and some opportunities for case discussion. Introductory workshops (either one-day or two-day), offer training with opportunities for reflection and discussion of issues such as the meaning / value / impact of defining people as having a PD. Participants are given an understanding of early developmental and relationship factors (including trauma, abuse and neglect) and service-users facilitate constructive discussion to explore issues specific to particular service contacts. The second introductory day offers a series of half-day modules focusing on specific skills and practical guidelines relevant to PD. Topics include: **a)** interpersonal skills

b) *managing violence and aggression*
c) *establishing appropriate care pathways*
d) *responding to self-harm and suicidal behav*iour
e) *providing containment and appropriate boundaries*

Level 2 training is still being developed but it is likely to incorporate specialist psychological therapies including Cognitive Analytic Therapy and Dialectical Behaviour Therapy to name a few with ongoing supervision requirements and the establishment of clinical networks. This innovative project has been funded for two years and consists of a strong research and evaluation component to ascertain its effectiveness and it is hoped that demonstrated effectiveness will encourage its future establishment within a wider Personality Disorder service. This will ensure that people with a personality disorder are less likely to be excluded from service provision.

Alex

EOP Update - South-West:

ExtraOrdinary People has been running for just over a year. The launch day for the project was June 29th. We saw people meeting in Exeter to talk about the label of personality disorder and what it meant for them. Since that day, there have been networking days in Plymouth, Torrington and Torbay, all with similar discussions taking place. With different people attending each of the days, there have been some very important points made - many of them similar across the South-West.

People have asked: 'What is Personality Disorder? What does it mean? What can we do? Where can we get help?' Lots of questions, frustrations and confusions. Answers aren't always external; they can and do come from within, from our own strengths as individuals. Those of us who have been in the patient or service-user role know only too well what it feels like to be put down by those who don't understand. That is not because they don't want to understand but rather that they haven't 'been there'. ExtraOrdinary People is about people who <u>have been there</u> helping people who <u>are there</u>!

We now need to get groups of ExtraOrdinary People to set up in various areas, places where one can go and feel listened to, can listen to others and feel respected. It's not about rocket science - it's about life!

Elaine

The National Picture

In 2003 the Department of Health published the NIMHE Policy Guidance entitled Personality Disorder: No Longer a Diagnosis of Exclusion. This publication initiated considerable development and interest around Personality Disorder services and training developments across England.

Whilst for a long time it was thought that people with a personality disorder did not respond to treatment, it is now recognised that many people do benefit from treatment and understanding how to work well with people with a personality disorder to enable them to recover more effectively should be something we are all working towards. However it is recognised that many people, staff and the public alike, find it difficult to understand peoples' behaviour which can sometimes be challenging and can lead to negative attitudes and practice. Hence, the Department of Health has been very keen to develop a whole system approach to working with people with a personality disorder which includes mental health services, criminal justice and forensic services as well as the wider health and social care community including accident and emergency services, primary care, voluntary agencies etc.

There have been a number of service developments for people with personality disorder which include forensic services as well as community based services. Six pilot projects were started for those involved with the forensic setting. Some of the forensic pilots were attached to prison services and special hospitals whilst others are working alongside community services. These developments happened because people became much clearer that personality disorder affects many people in prisons, probation and other areas when in fact they may never come into contact with mental health services.

In 2004 eleven pilot sites were started across England which provide services within general mental health care settings. They are very different in how they work. Some such as the SUN project in South West London offer a user-focused initiative to develop networks which offer support and befriending opportunities to people who could be diagnosed with a personality disorder. Other projects work more with statutory organisations such as health and probation to offer advice and provide good sound management for people with a personality disorder to ensure that they get access to services as necessary with the most appropriate treatments. Some more traditional projects offer day centre treatment for a small group of people within a therapeutic community type environment. Our most local pilot is in Plymouth and works with people under 25 who have complex behavioural needs and the Early Intervention team work to improve connections for young people with housing, education, and employment as well as sometimes helping them access more specialised treatments as the need arises.

Therefore, as you can see, there are many different ways of working with people with personality disorder and what seems to be important is to recognise that having choice around what is available to people is a much better way forward as not every-body requires intensive treatments, some benefit substantially from working with others who have had experience of personality disorder themselves.

The Department of Health is currently evaluating all services and a report will be available next year which might give us some ideas about what is an effective treatment and what people find is most helpful.

Alex