

A user-led survey of people with a personality disorder diagnosis finds a group more sinned against than sinning

A dangerous diagnosis

The modern concept of personality disorder is represented by two connected notions: either that the personality abnormality causes problems to self and/or others or that the behaviour is so anti-social as to be dangerous to society. The American and European psychiatric diagnostic manuals refer to personality disorders as 'enduring patterns of behaviour that deviate markedly from the expectations of the individual's culture', and 'pervasive, inflexible deficits that are stable over time'. This gives the service user little cause for any hope at all. It is a category that does not have much scientific credibility and it is a diagnosis that is often hidden from patients, and one where untreatability is still a widely held belief.

This article tells the story of a study carried out for and by service users with a personality disorder diagnosis. The idea for the research came through a group of local service users with the diagnosis, who contacted the advocacy service run by Mind at the acute mental health unit at Colchester general hospital. I had advocated for most of them for some years and we had established an association and trust. The spark was the publication by the Home Office and the Department of Health in July 1999 of proposals for managing so-called dangerous people with severe personality disorder, which would consign them to special units as a preventive measure even if there were no deterioration in their clinical state.¹ We began to hear from anxious service users who had at some time received the personality disorder diagnosis or had at one time assaulted another person, however minor the incident. Their fears were not calmed by the government's assurance that indefinite detention would apply only to a tiny number of people.

We decided to seek an account, from their own experiences, of the inner world of people who have been given a diagnosis of personality disorder.

Our group of 18 met monthly throughout 1999. Five expressed a wish to train as research interviewers to conduct the fieldwork and embarked on a training programme devised with the assistance of Anglia Polytechnic University for this purpose. We obtained a research grant from the university so we could pay the researchers £30 for each interview and participants £10 for their time.

It is important to understand that the researchers were not 'survivors' engaged in a retrospective study but rather 'sufferers' struggling for emotional equilibrium while engaged in a research endeavour. Ever-present was the question of who might relapse next and ethical dilemmas about the stressful nature of the work and how that might be affecting the researchers. Our five researchers reduced to four almost as soon as the training programme began, and two of these were admitted to hospital in the course of the study. The other members of the group continued their support, joining us to meet each month, some from hospital wards, some even when under section.

Our research approach was emancipatory, described by Freire² as an approach that challenges the validity of the privileged analysing the underprivileged. With the help of two skilled supervisors from Anglia Polytechnic University we created an interview questionnaire that used a blend of qualitative and quantitative methods, starting with a semi-structured interview to give primacy to the voice of the service user. We asked them what the term 'personality disorder' meant to them; how they found out about their diagnosis; what they would say were their problems; the implications of the diagnosis; their experiences of mental health and other services and what, in an ideal world, they wanted from the services with which they were in contact. We also asked them what they saw as their strengths; it was, we felt, important to counteract the uniformly negative attributions of the diagnosis. The quantitative component comprised a →

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→ series of demographic, tick-box questions about gender, ethnic origin, family and domiciliary and employment situations. The group advised on the wording that would make the questionnaire real and understandable to fellow service users. We set a target of 50 interviewees as a number that would carry credibility. Obtaining permission from the local research ethics committee was fraught. It took over three months' negotiation before permission was granted. Most of the debate was around confidentiality. We finally obtained permission in August 1999 and completed all 50 interviews by the end of December. Participants were accessed almost entirely by networking and 'snowball sampling'.

Categorised

The full findings can be found in the book *Personality Disorder: Temperament or Trauma?*, published by Jessica Kingsley this month. This article summarises some of the findings. Over half (58%; n=29) had been given a diagnosis of borderline personality disorder, 28% (14) had a diagnosis of dissociative personality disorder and 14% (7) said their personality disorder diagnosis was unspecified. There was a clear gender bias: over 75 per cent of those with borderline diagnoses were women and over 75 per cent of those given dissociative diagnoses were men.

All had been given additional diagnoses. The most common were depression (78%) and anxiety (60%), followed by eating disorder (34%). Also reported were manic depression (22%), obsessive compulsive disorder (20%), schizophrenia (14%) and post-traumatic stress disorder (12%). The majority (86%) described their own difficulties in terms of depression or anxiety, and often combinations of both. Morrison³ argues that the personality disorder diagnosis is probably applied to a far greater proportion of patients than necessary because so many people can be shoehorned into its capacious definition, and that many have more easily treatable disorders, including major depressive disorder. A psychiatric perspective may be that such a categorisation is simply that: a category that identifies a type of disorder that is not mental illness. 'It exists. It needs to be recognised and categorised, but it is not our business because it is not a psychiatric illness.' The effect is to consign those so diagnosed to a hinterland devoid of real legitimacy, leaving them disadvantaged from the start in terms of response and treatment.

Four interviewees had recently been given a re-diagnosis of bipolar or mood disorder. These excluded, was there a link among the remainder? The data revealed that 88% (44) had suffered abuse, violent, sexual and/or

Regardless of which category of personality disorder, the study thus showed high incidences of early abuse, self-harm and suicidality.

Twenty per cent of the study were women who had been violent to others and 22 per cent were men. The women with a dissociative diagnosis all had a history of emotional abuse but not violence in childhood; 67 per cent of them had been violent to others. Where men had experienced early violent abuse, some went on to harm others and some engaged in self-harm. These findings suggest that violence does not necessarily beget violence; it does suggest that early, unresolved trauma can result in the perpetration of harm, whether directed inwards as self-harm or outwards as harm to others.

Comments offered by the interviewees on their diagnosis and the reactions of services highlight the sense of exclusion and hopelessness connected to the diagnosis and its impact on individuals already struggling to live with the fact of an early abusive history:

'A dustbin label given to people who seem difficult.'

'Life sentence – untreatable – no hope.'

'Treated less sympathetically ... not mental illness – something you've brought on yourself.'

'Told I was attention seeking. It was the worst thing I could have been told because I was crying out for somebody to help.'

Asked what they wanted from services, people told us:

'Less medication, more talking to find deep-rooted problems. Not to give diagnosis willy-nilly when there's so much stigma attached.'

'Treat me like a human being, not an animal.'

'Staff to change their attitude and become more sympathetic.'

The responses corroborate the description of the diagnosis as carrying maximum stigma and minimum therapeutic value,⁵ and certainly 72 per cent of the sample felt they had experienced bad treatment because of the label. As one respondent wrote at greater length: 'It is no wonder that those of us with a personality disorder diagnosis feel like second – or more like third class citizens (life's rejects). You only have to look at the

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emotional, and for 80% (40) this was childhood abuse. The four who had achieved a re-diagnosis had no such history. Symptomatology (see table one) showed notably high rates of suicidality (82%) and self-harming behaviours (88%). These findings suggest empirical support for the concept of a post-traumatic syndrome in survivors of prolonged and repeated victimisation.⁴

definitions given in ICD 10 and DSM IV and read comments such as: "Limited capacity to express feelings – disregard for social obligations – callous unconcern for others – deviant social behaviour – inconsiderate of others – incompetence – threatening or untrustworthy". The list is endless but one thing these comments have in common is that they are not helpful in any way.'

Table one: Symptomatology (n)

Cutting	32	Destroying things	28	Disassociated / Separate	28
Other types of self-harm	24	Being exploited	23	Imprisonment	19
Overdosing	39	Exploiting others	3	Relationship difficulties	41
Suicide attempts	41	Hospitalisation	44	Abandonment	25
Alcohol misuse	23	Sectioned	30	Loss of children	19
Drug abuse	15	Juvenile convictions	6	Early sexual abuse	21
Overwhelming anger	37	Adult convictions	25	Early violent abuse	23
Desire to hurt others	24	Rejection from services	25	Early emotional abuse	39
Violence to others	21	Isolation	39	Later abuse	30

Table two: Experiences

Theme	Total	Female	Male	Borderline female	Borderline male	Disocial female	Disocial male	Unspecified female	Unspecified male
Sample	100%	60%	40%	46%	12%	6%	22%	6%	8%
Self-harm	88%	54%	34%	91%	83%	100%	82%	75%	100%
Suicidality	82%	52%	30%	96%	67%	67%	64%	100%	75%
Violence to others	42%	20%	22%	35%	0%	67%	64%	0%	100%
Imprisonment	38%	12%	26%	13%	50%	67%	73%	33%	50%
Early sexual abuse	42%	36%	6%	70%	17%	33%	9%	33%	25%
Early violent abuse	46%	28%	18%	51%	17%	0%	55%	67%	50%
Early emotional abuse	78%	50%	28%	87%	50%	100%	73%	67%	75%

Understanding

Our research report was completed in February 2000, at the start of the new millennium. Of our four user-researchers, one has been discharged from mental health services altogether, one is preparing to resume his degree that was interrupted many years ago by mental illness and one works as a mental health advocate in another hospital. Others involved in the wider group have moved on, got married, managed to get their children back, started academic courses and begun part-time work. Yet others continue to struggle badly and for this reason we reformed the group at the beginning of 2001. Some members continue to report experiencing great difficulties with access to meaningful support and services.

On 25 June 2002 the draft Mental Health Bill was submitted to parliament. The preceding white paper had set out the proposals for dangerous and severe personality disorder in a separate section.⁶ The term has, however, been left out of the draft Bill, in an attempt perhaps to sidestep the diagnostic confusions or the lack of credibility as a diagnosis. The term 'psychopathic' has also been removed and the language is generally more respectful. Mental disorder is defined as: '... any disability or disorder of mind or brain which results in an impairment or disturbance of mental functioning.' The disorder must be 'of such a nature or degree as to warrant provision of medical treatment' and, 'in the case of a

patient who is at substantial risk of causing serious harm to other persons, that it is necessary for the protection of those persons that medical treatment be provided'. It is not difficult to deduce that the new definition of mental disorder is designed to close the treatability legal loophole in the current Act that has made it difficult to remove from society those considered to be dangerously disturbed unless they have committed a crime.

'I was in hospital for a bipolar condition. My diagnosis was changed by a locum psychiatrist. Within a few days I was discharged without money/benefits, medication or proper aftercare, into inadequate accommodation, with so-called "untreatable personality disorder". I fell into the hands of the police as I was wandering around [the town centre] aimlessly and for two nights I was held in a police cell because I was so ill. The consultant would not re-admit me, either informally or under section...'

One might argue that such an Act might broker a better deal for service users like this individual who came to the advocacy service for support. It would at least offer access to treatment. However under such an Act would a new kind of 'disliked patient syndrome' emerge? Under the current Act it can be decided that someone is not mentally ill but rather personality disordered and untreatable. Tomorrow it may be that they are considered simply to be criminal. →

What does it mean?

What does personality disorder mean to you?

Don't know	26%	(13)
A label you get when 'they' don't know what else to do	22%	(11)
Mood swings/Personality change	18%	(9)
Bad/Labelled	10%	(5)
Identity	6%	(3)
Developmental	6%	(3)
Self-destructive	6%	(3)
Relationship difficulties	4%	(2)
Dissociation	2%	(1)

What do you consider to be your problems?

Depression/Depression + other	36%	(18)
Abuse/Blaming self	28%	(14)
Stress/Not coping	22%	(11)
Substance misuse	14%	(7)

Implications of the diagnosis

Treated badly	44%	(22)
Mixed/improved	20%	(10)
No difference	10%	(5)
Treated badly by social services	8%	(4)
Good support	4%	(2)
Picked up by police	4%	(2)
Caused by self	4%	(2)
Treated differently in prison	2%	(1)

What would you like in an ideal world?

Better service response	34%	(17)
Out of hours/Safe house/Helpline	12%	(6)
Label changed or responded to differently	12%	(6)
Activities/Occupation	10%	(5)
Home and family	8%	(4)
Better parenting help	8%	(4)
Safe world for children	4%	(2)
Not to need services	2%	(1)
Less urban alienation	2%	(1)
Second chance	2%	(1)

What has helped most?

Family	36%	(18)
Therapists	34%	(17)
Advocacy	34%	(17)
Medication	26%	(13)
Voluntary sector	24%	(12)
Psychiatrist/Hospital/Hospital keyworker	24%	(12)
Community mental health teams	22%	(11)
GPs	14%	(7)
Friends	14%	(7)
Other clients	10%	(5)
Church/Spiritual beliefs	10%	(5)
Accommodation	8%	(4)
Child care	4%	(2)
Education	4%	(2)
Independence/individuation	4%	(2)

→ Locally service users continue to campaign for preventive treatment strategies and against preventive detention. Their aspirations include the more comprehensive provision of psychotherapeutic treatments such as cognitive analytic and dialectic behavioural therapy, the provision of day services run as therapeutic communities and the opening of a local safe centre and crisis house. The Department of Health is currently working on a national personality disorder strategy, the publication of which is imminent. Representatives from our area were invited to join the service user focus groups consulted. In the words of one of them: 'I found it encouraging because the way the Department of Health was coming across made me feel as if they really want to do something. I felt that the lack of services and appropriate support was really highlighted. You can experience decades of abuse and are expected to get better in a few months, whereas sometimes years of treatment is needed. People ask for help, and they ask and ask. Eventually something drastic happens and it's too late – suicide or murder.' But local service users remain sceptical about the implementation of their views. With a proposed investment of some £120 million into specialist services for people with dangerous severe personality disorder, they wonder how much will be left over for local mental health service provision and preventive work with young people.⁷

As far as we are aware, ours is the first full scale research study to have involved service users directly in researching clinical and diagnostic issues and to have explored in depth the experiences of people with a personality disorder diagnosis. We believe our study demonstrates that a group of service users can produce something new and fruitful in the field of mental health research. Service users have shown that people who are still in the midst of their difficulties can, with support, effectively and powerfully define themselves within a system and so contribute to scientific knowledge. Their findings point overwhelmingly to a need for a more humane response and a redefining of the personality disorder diagnosis to one that more clearly suggests aetiology and offers a better understanding of this human condition. ■

Heather Castillo's book *Personality Disorder: Temperament or Trauma?* is published by Jessica Kingsley £18.95 ISBN 1 84310 053 3. Readers can obtain a copy for just £15 (p&p inc) by telephoning the publishers on 020 7833 2307 and quoting 'Mental Health Today'

- 1 Department of Health. Managing dangerous people with severe personality disorder. London: Department of Health, 1999.
- 2 Freire, P. Pedagogy of the oppressed. New York: Herder and Herder, 1970.
- 3 Morrison J. DSM IV made easy. London: Ilford Press, 1995.
- 4 Herman J, Van der Kolk B. Traumatic origins of borderline personality disorder in psychological trauma. Washington DC: American Psychiatric Press, 1987.
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- 6 Department of Health. Reforming the Mental Health Act. London: Department of Health, 2000.
- 7 Oats P. Is there a need for a new label in mental health? *Personality Disorder North Essex News* 2002; 14: 2.