

**Heather Castillo, Lesley Allen & Kathy Warner** on 'emancipatory research' by people diagnosed with personality disorder

# Crossing the borderline

Personality disorder continues to generate a kind of moral panic in society, although its clinical definitions range from the most timid to the most dangerous among us. The diagnosis is characterised by confusion and lack of agreement. Where understanding is required, fear has emerged instead.

New legislation is currently being considered for those defined as suffering from dangerous severe personality disorder (DSPD). It is then proposed that people placed in such a contested category, which has caused many problems in terms of treatability, will be legislated for differently, singled out for preventative detention on grounds of public safety.

In our local area, a growing number of disaffected clients seeking support from Colchester Mind Advocacy Service appeared to have a sole or combined diagnosis of personality disorder (PD). Our attempts to help find solutions to their complaints were largely ineffective. The impulse to form a research group came in July 1997, when a consultant in public health published an article in the *Guardian* entitled 'Everyone's life has a price'. He suggested that money could be saved by denying hospital admissions to those diagnosed with personality disorder. A local service user responded to this article by writing a letter from hospital: 'I am a victim of childhood sexual and ritual abuse... I am not yet a "survivor"... I don't see why I should be deprived of the care and expert counselling that I most definitely need. It was, after all, not me who carried out abuse on a minor. I am just trying to cope with the aftermath'.

Our group began to research the medical model of pd, a diagnosis that causes great suffering for many who receive the label. The user-researchers involved were not 'survivors' engaged in a retrospective study, but 'sufferers' struggling for emotional equilibrium while engaged in research.

The group was made up of eighteen service users with a pd diagnosis. Experiences were shared, and nine group members then created written narratives exploring life events. Four members were trained to interview fifty people diagnosed with pd in north east Essex. Our five interviewers became reduced to four almost as soon as the training programme had begun. Two of the remaining four were admitted to hospital during the course of the study. All four researchers negotiated very great personal difficulties during this time. Other group members also experienced problems, yet they still came to join us each month. Some came from the hospital ward. Some came even when 'sectioned.' One responded from prison. The commitment was breathtaking.

The literature shows that people in this category are often misunderstood and stigmatised, but that dysfunctional behaviour can be trauma related, and distorted attachment experiences in childhood result in a dissociative core self.<sup>1</sup> The findings of the study indicate that, for a significant percentage, life events involving early trauma may be at the root of the disorder. Eighty-eight percent of those interviewed had experienced abuse, 80 per cent in childhood.

To be subsequently labelled with personality disorder is very stigmatising, and can compound the effects of trauma. Respondents described being 'treated as a services leper', 'with

hostility', 'given a wide berth' and 'ignored'. They were also told that pd was 'not mental illness' and was 'brought on oneself', and meant you were 'a trouble maker'. Many service users only discovered indirectly that they had been given the diagnosis – from records, reports or at social services meetings. Others appear only to have been told many years after they were diagnosed, and often only after they asked. On making this discovery, the sense of exclusion and hopelessness expressed by respondents – who are already struggling to come to terms with past abuse – is profound.

The research also revealed a gender association between borderline and dissocial personality disorder, the two commonest categories. More than 75 per cent of the women had received a borderline diagnosis, and more than 75 percent of the men a dissocial diagnosis. Twenty per cent of women had been violent to others and 22 per cent of men. None of the borderline men had been violent to others. Thirty-five per cent of the borderline women had engaged in violent acts, yet had retained the borderline diagnosis. Does this suggest that violence in men might attract a diagnosis of psychopathy more easily than for women? Twenty-six per cent of men in our study had been in prison, compared with 12 per cent of women. Does this indicate a greater likelihood of prison on the basis of gender?

Fifty per cent of dissocial men in the study considered their strengths to be care and compassion. Rather than the stereotypical notion of the psychopath viewing fellow human beings as 'empty vessels', they characterise themselves as Jekyll and Hyde, an embodiment of both compassion and aggression. They highlight the fact that aggression has a context, and that strengths may go unrecognised. Whether the categorisation is borderline or dissocial, our study shows high incidences of early abuse, self-harm and suicidal feelings.

Employing an emancipatory research approach, the service users diagnosed with pd have created a new construct about the disorder, which incorporates triggers, contexts, symptoms, coping strategies and insight into the effectiveness of interventions and treatments. The findings highlight differences between service users' own descriptions of the disorder, and those in the accepted clinical manuals. This points overwhelmingly to the need for a reframing and renaming of personality disorder, to offer a better understanding of this human condition.

In a service where many professionals work together as part of a team, the outsiders in this process are not only those who are suffering the most, but also those who have a great amount of experience and insight. It is now becoming desirable for a wheelchair user to advise on services for people in wheelchairs – but such advice about services is not so desirable if you have mental health problems, especially a diagnosis of personality disorder.

It is hardly encouraging to learn that your condition is considered by some to be untreatable. There may be individuals for whom treatment is difficult and prolonged, and even those who will, from time to time, 'bite off the hand that feeds them'. However, there are reasons why this is so, and those of us who have attracted the

