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. 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 percent 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 experienced 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 disocial personality disorder, the two commonest categories. More than 75 percent of the women had received a borderline diagnosis, and more than 75 percent of the men a disocial diagnosis. Twenty percent of women had been violent to others and 22 percent of men. None of the borderline men had been violent to others. Thirty-five percent 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 percent of men in our study had been in prison, compared with 12 percent of women. Does this indicate a greater likelihood of prison on the basis of gender?

Fifty percent of disocial 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 disocial, 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
diagnosis understand what those reasons are. As potential contributors to this research, some of us felt useless and hopeless because our sufferings are often not believed or taken seriously. We decided we could contribute best by writing. We needed to write. We needed to put these sufferings into words. There are reasons and contexts that are not given legitimacy. For example, someone who has been cut and raped may cut themselves again in the same place. We want to let these feelings go, but often simply cannot. Recognising us as survivors of abuse might go some way towards a clearer definition of this condition, but trauma is a more inclusive term, encompassing both cause and condition. This category, if anything, is about harm. Most of us harm ourselves. We cope in this way. A minority also harm others. Whatever the effects of our difficulties, we ask you to remember that we are human, we are traumatised and we are usually full of pain.

Mental health professionals cannot fully assess the quality of their work unless they seek the views of those affected by it. When service users are conducting the study, a new paradigm in research is created, where the view from the outside is replaced with the view from within. In this study the research tools have been given to ‘the people’ and with them they have been able effectively and powerfully to define themselves within a system and so contribute to scientific knowledge. However, if user research is to move beyond user-focused-monitoring, and is to become an integral aspect of the clinical governance system, service users will require support. Our research was supported not only by Colchester Mind, but also by Anglia Polytechnic University who provided training and funding. Without this support it is unlikely our efforts would have proved as sustainable. In north Essex, the health authority and social services are considering the creation of a user involvement project, which will foster this type of user initiative across the region.

Illustration by Richard Priestley.