

Dialogue

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Part of the Virtual Institute of Severe Personality Disorder

LINKING PROFESSIONALS AND USERS WITHIN THE PERSONALITY DISORDER FIELD

Editorial

Welcome to the fourth edition of *Dialogue*! We have now been in circulation for a year and in order to identify the readership of *Dialogue* and gauge your satisfaction with the newsletter, **we would be grateful if you could complete and return the evaluation form enclosed.**

Dialogue is a project funded by the Department of Health's National Programme on Forensic Mental Health Research and Development, with the

aim of promoting research and development within the personality disorder field. *Dialogue* is a vehicle via which to disseminate current research findings, comment on mental health proposals, inform about new service developments; advertise new training courses; update clinical information; report personal experience of treatments; and publicise forthcoming events, but above all to exchange views. We aim to facilitate a dialogue between professionals and service users to inform and improve the service provision available. In order for this to be effective, **we actively seek articles from both professionals and**

service users. This is your chance to air your views. The articles can be brief or more detailed, but of no more than 750 words.

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Sue Ryan,
Editor

Personality disorder user research

The professional and public debate regarding personality disorder (PD) has remained largely uninformed by the user perspective. However, in north east Essex during 1999, a group of 18 service users who had attracted this diagnosis set out to study the problem from the 'inside'⁽¹⁾. With the help of Professor Shulamit Ramon, of Anglia Polytechnic University, and Dr Nicola Morant, former researcher from the Henderson Hospital, Colchester Mind trained and supported four members from the group to interview a further 50 people with the PD label. The resulting

research is called '*Temperament or Trauma?*'⁽²⁾. This study may be the first nationally where service users have investigated, analysed and redefined their conferred diagnosis, and have presented a new construct for consideration by legislators and mental health professionals.

Our research includes almost 15,000 words from service users, which show us not just how they are, but how they came to be that way. Findings reveal that 88% have experienced abuse and that, for 80%, this was childhood abuse. The results of our study, and a review of

literature, show that the devastation that results from early trauma is a violation of personal boundaries, which may result in a dissociative core-self. Not being able to find oneself from within, an individual is forced to find a sense of self from the outside by treating themselves as an object or by getting others to react to them⁽³⁾.

Seventy-two per cent of service users in this study consider they have experienced bad treatment because of the label. Confirming that the diagnosis is

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<http://www.visped.org/index.html>

Views from service users

The day I shaved my head

Some decades ago I was sitting in an office at the local 'bin' where a registrar was supposedly reviewing my current 'treatment' which was Prozac, and was decidedly not helping me. The registrar and I had never met before, he was just one in a long hazy line of faces. Over the last thirty years I have been the recipient of tranquillisers, stomach pumps, hospitalisation, music therapy, group therapy, exorcism, art therapy, psychodrama, counselling, cognitive analytic therapy and even sex therapy (this from a GP who recognised my vulnerability, loneliness, desire to please and tendency to blame myself). Luckily I

avoided ECT when it was suggested back in the late 1960s.

But here I am, in the mid 1990s with a registrar who inadvertently informed me that I was not going to receive psychotherapy. My reaction to this was initially shock and disbelief, which quickly turned to tears of anger. He summarily dismissed me as I fled to the ladies and sat in a cubicle mopping the tears, wondering how on earth I would get home. I had lost hope and was feeling utterly desolate and worthless. In my bag, I had some nail scissors and as I splashed water on my face, I noticed my long red plait – the only thing I like about myself. I took the scissors and cut it off.

When I got home I tried to tidy my shorn locks and I cut closer and closer to the scalp. It seemed that all the anger, frustration and pain flew into the scissors. I suddenly knew what I must do, having come this far – shave my head. A stranger looked back at me in the mirror. On my head, I discovered a birthmark and a small mysterious scar. The pain and chaos disappeared. I felt a welcome calm, lighter both physically and mentally, and experienced a strange sense of pride and a defiance that perhaps gave me the energy to carry on. It felt like a re-birth, providing a vital distraction at such a low point in my life.

Margy H.

Service User

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stigmatising, respondents describe being treated as a 'service leper', 'let's give her a wide berth', 'you're ignored', 'hostility', 'not mental illness', 'brought on one-self', 'people seem to be scared of the diagnosis', 'it's saying trouble-maker'. Many service users discovered, indirectly, that they had the diagnosis, from records, reports, or at social services meetings. Others appear to have been told after many years, some professionals telling service users only after they asked. The sense of exclusion and hopelessness expressed by respondents making this discovery gives some insight into the impact the information might have on an individual labouring with the desperately hard task of living with the truth of an early abusive history.

In this study, 88% claim to have experienced hospitalisation and 60% have been 'sectioned'. For some, the association with mental health services spans decades; for others it is more than ten years. Seventy-eight per cent experience isolation and 88% are living on welfare benefits. Many are still depressed and anxious. A 'revolving-door' syndrome may say something about the need for a wiser use of limited

resources. Even where the anti-social aspect of destructive behaviour may lead to a perception that someone is less deserving of health care, this can still place a high demand on health, as well as social and criminal justice services, suggesting that effective and lasting therapeutic treatments should not be considered an expensive luxury⁽⁴⁾.

Post-traumatic stress disorder is a category included in DSM IV⁽⁵⁾ and ICD 10⁽⁶⁾, as is DESNOS – disorders of extreme stress not otherwise specified (DSM IV), and enduring personality change not attributable to brain disorder or disease (ICD 10). However, neither category in ICD 10 acknowledges early childhood trauma as valid criteria for inclusion. Therefore, where an individual's symptoms include features such as the kind of **complex stress disorder** described in our study, there is no adequate diagnostic category to give validity to such difficulties. This points, overwhelmingly, to the need for a reframing and renaming of the diagnosis into a category which more clearly suggests aetiology, and offers a better understanding of this human condition.

'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 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 that these comments have in common is that they are not helpful in any way. All I know is that we cannot call ourselves a civilised society when so many people are outcasts and are simply not understood.'

Heather Castillo, Colchester Mind and Lesley Allen, Service User

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