Working outside the diagnostic frame

We cannot abandon the injured or the maimed, thinking to ensure our own safety and sanity. We must reclaim them, as they are part of ourselves.
Brian Keenan (1993, p.288)

RUFUS MAY *on rethinking 'sanity', within a community psychology approach.*

THE other articles in this special issue have outlined some of the conceptual problems with psychiatric diagnosis. In this article, I'd like to describe some of the problems caused for mental health service users by diagnosis and clinical language before moving on to describe how it is possible to work clinically with people experiencing severe emotional distress *without* using psychiatric diagnosis. The work I describe best fits with a broader community psychology model, which places the ethics and politics of experiences of service users at the heart of its approach.

The side-effects of diagnosis

The diagnostic process converts someone's distress from a psychosocial problem into an individual problem – it takes the person's experience out of its social and historical context. Despite the well-recognised problems with the validity and reliability of diagnostic categories like schizophrenia (see articles by Richard Bentall and Mary Boyle in this issue), they continue to be used by psychiatrists and many clinical psychologists.

However, a much-neglected issue in these debates is how mental health service users experience being given a diagnosis. For example if a person is given a diagnosis of schizophrenia they and the people around them can acquire a learned hopelessness; a person with bipolar disorder can resign themselves to a period of depression after a period of being high; a spiritual experience can feel written off if it is described by clinicians as a delusion. Eleanor Longden (2005, p.35) eloquently brings this alienation process to life:

You feel as if you've passed from romance to realism in one wretched step. You feel at the mercy of events; even though you know events have no mercy in them. I can't ever explain; the way despair feels is only an approximation… I stopped being Eleanor then and instead became 'that schizo'. From fear of darkness came fear of light… Friends ceased to be friends, because they wanted me as they remembered, which was solid, capable and sane.

As Peter Campbell notes in his article in this issue, one of the criticisms made by the mental health service user and survivor movement over the years has been that professionals tend to focus on professional interventions and neglect the expertise of service users. In my work helping people in distress and confusion, I have attempted to redress this balance by adopting a community psychology approach (Scileppi *et al*., 2000) which puts service users' views and experiences at the centre (see May, 2004, for a fuller discussion).

I place considerable emphasis on self help, group-work and community meetings. In working clinically with groups, communities and individuals, I draw on insights from a variety of sources. For example, the recovery movement have argued for a move away from a clinical fixation on symptoms and to embrace broader notions of what recovery means – like increasing quality of life (e.g. Repper & Perkins, 2003). The user movement has emphasised the importance of self-determination (e.g. Rose, 2001; Wallcraft *et al*., 2003) – independence, and defining your situation as you see it – whilst the Hearing Voices Network notes the importance of respecting a variety of explanations for distressing experiences (Downs, 2000).

I find it useful to focus on exploring frameworks that enable meaning to be made of a person's experiences and actions that will help reduce distress and increase psychological and social functioning. I try to create an atmosphere of acceptance, understanding, optimism and hope. Helping people describe their experiences in their own terms (e.g. feelings of dread, hearing voices, dissociation, panic, despair) is more respectful than trying to fit a person's experiences into a diagnostic category.

Working in the person's reality

Whatever their diagnosis, a major problem for people receiving help from mental health services is their social isolation. Introducing people to others who have some commonalities in their social situation or experiences can be more helpful than any psychological intervention in many cases.

One of the implications of respecting a variety of explanations for someone's experiences is to create spaces where different beliefs about the nature of reality are accepted (Knight, 2005; Romme & Escher 1993). Self help groups are good places for this to occur – the Hearing Voices Network is an excellent example of a community of service users whose

success in reducing distress through group identification and support is now well recognised by a growing number of professionals.

Professionals can also act as allies to service users in helping to create democratically run spaces for them to exchange support, relate experiences and be role models for each other. For example, in Bradford I facilitate a hospital-based recovery group which aims to do this. In diagnostic ways of working, unusual beliefs may be considered delusional and a symptom of an underlying biological illness. However, the premise of our meetings is that the belief is not the problem in itself. Rather, the problem is the distress such beliefs may cause us and the problems we face in negotiating such beliefs in the wider social world we live in. By finding a safe space to share a distressing belief or experience, the process of being listened to compassionately can bring a great deal of relief. We can then look at different ways to reduce the associated distress together.

Working inside and outside psychology

In the psychological literature, awareness of the important role played by religious and spiritual beliefs in people's experiences of their distress is increasing. Many service users frame their problems in spiritual and religious terms and there is a growing interest in the associations between experiences which are viewed as psychotic and spiritual experiences (e.g. Clarke, 2002).

Mental health services – which have, in modern times, been traditionally secular – have viewed such understandings with suspicion. However, if a service user holds a spiritual explanation and believes that a religious ritual (e.g. exorcism or 'redemption') may help them, then it may be useful to work within the person's reality and with their faith community. In the UK, the existence of diverse cultural communities means that, as psychologists, we need to be able to sensitively address the variety of religious and spiritual beliefs that exist, in a way that is considerate and respectful. It is important to have contact with trusted, compassionate and psychologically-minded faith community elders like a priest. Douglas Turkington, a psychiatrist, has spoken about similar work (James, 2002).

Of course, spiritual and other

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perspectives have implications beyond the level of the individual. One person in a hearing voices group proclaimed 'I believe we're not mad, we're gifted'. Another voice hearer responded 'yes it's a gift but badly wrapped'. Can the perception of alternative realities or the experience of extreme pain have a meaning or a purpose in our lives? Many people, for example, find it useful to see madness as a creative way of dealing with emotional pain. Many recovery stories describe how decoding the meaning in madness can lead to understanding and addressing emotional injustices that have occurred in the past. The spiritual teacher Krishnamurti said: 'It's no measure of health to be well adjusted to a profoundly sick society', and we may have a lot to learn from experiences society deems as mad. Indeed, the campaigning group Mad Pride aimed to reclaim the notion of madness in the way many marginalised groups have done in the past (Dellar *et al.*, 2000).

Embracing a variety of explanations of distress may cause us to rethink notions we take for granted, like normality and sanity. It may also raise questions about the role for psychologists in addressing issues relating to mental health and distress, as it tries to move away from the traditional curative model. In embracing the community psychology approach, I have helped create a series of public meetings in West Yorkshire called Evolving Minds (see weblinks) to explore different understandings of, and approaches to, mental health. In various ways the meetings have questioned the logic of society's parameters around sanity and

insanity – in one of our meetings, for example, we discussed 'how do we survive in a sick society?'.

Finally, I have found it is important to create space for people to express their anger or hurt feelings about discrimination they have experienced in relation to diagnostic thinking. Where possible I will support people to find ways to speak out about these experiences, contributing to the growing pressure for political change in society's approach to distress and confusion. I have become involved in campaigning for better rights for service users (e.g. May *et al.*, 2003). I would encourage my fellow psychologists to recognise the ethical and political issues surrounding diagnostic and curative models of mental health and distress, and to build this awareness into their approach.

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