Invisible walls:
Madness, distress and the boundaries of credibility

Abstract
This paper describes a conceptual model for thinking about different understandings of mental health and illness. I use this model to identify tensions that exist in mental health policy and practice in Australia, and some of the consequences that flow from these. I argue that in Australia, disciplinary and service cultures are grounded in differing and unarticulated assumptions about the meaning of service users’ experience. These differences create barriers to communication between practitioners working in different service types. They also make it difficult for service users, carers and newcomers to the sector to make sense of what they hear. Unarticulated assumptions construct invisible walls, marking the boundaries that separate views that can be regarded as credible in conversations about mental health, from those that cannot.
Invisible walls:

Madness, distress and the boundaries of credibility

I came to mental health research several years ago as an outsider. One of the first things I noticed was that what seems to be true or obvious in thinking about mental health differs according to where you look from. Researchers, like service providers and people who use mental health services, are situated actors. We use the conceptual tools available to us to make sense of what we see (Smith 1999:59, 1990:206). In this paper I describe a model I have found useful in thinking about different understandings of mental health and illness. I use this model to identify tensions that appear in mental health policy and practice in Australia, and some of the consequences that flow from these. I then consider some recently published first-person accounts of madness, and the responses they have received. I argue that unarticulated assumptions about service users’ experiences act as invisible walls that mark the boundaries of credibility in conversations about mental health. A conceptual model such as that presented here is one way of making these assumptions visible.

Illness and distress

Ways of thinking about mental health and illness can be mapped along a continuum, like this.

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<th>Illness:</th>
<th>Distress:</th>
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<tr>
<td>Biology (content has no meaning)</td>
<td>Biology and environment (meaningful as metaphor)</td>
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<td>Treatment: Medical, by doctor</td>
<td>Support: Best from peers</td>
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Ways of thinking about mental health and illness
At one end is the view that people diagnosed with psychotic disorders are suffering from an illness that should be understood in biological terms, and treated with medication prescribed by a psychiatrist. This perspective regards voices and odd beliefs as symptoms; their content has no meaning, and the aim of treatment is to suppress them. This view is promoted by many psychiatrists, particularly in the US (Hornstein 2009:52).

At the other end is the idea that experiences like this should be understood not as illness, but as ‘unshared realities’. From this perspective, the content of voices and odd ideas is important, having meaning either as metaphor or as literal truth. People who are distressed by unshared realities benefit most from learning to understand their experiences. In this endeavour, the most effective support is that offered by peers. This perspective recognises that unshared realities are not always distressing. The aim of support is to enable people to live with their realities, not to suppress them: the focus of advocacy is on valuing difference. These ideas are developed in the work of consumer advocates and researchers such as Tamasin Knight (2009) and Shery Mead (2010).

In between these positions is the view that people diagnosed with psychotic disorders are suffering from an illness, whose causes can be understood in terms of biology and life experience. Treatment can include medication to suppress symptoms, along with talking therapies provided by a psychiatrist or psychologist. The content of voices and odd ideas might have meaning as metaphor: they can be seen as messages, pointing to wounds inflicted by past experience. The aim of talking therapies is to help the person understand their symptoms in relation to the context of their lives, thereby robbing the voices of their power and enabling the sufferer to relinquish their odd beliefs. This view is promoted by psychiatrists such as Paul Valent (2009) and psychologists such as Dorothy Rowe (2002). (For discussion see Hornstein (2009), Rogers and Pilgrim (2006) and Bentall (2003).)

Most of these ideas think in terms of illness. The ideas on the right-hand side of the line do not. At the cusp, straddling the line between illness and not-illness, are survivor groups like the Hearing Voices Network (2009) that are grounded in the work of Dutch
psychiatrist Marius Romme (Romme and Escher 2000; Romme et al 2009). Views at this position argue that voice-hearing is a normal experience, and it can be an enriching one. It is for each person to decide whether to see themselves as being ill.

American psychologist Gail Hornstein (2009) describes the orientation and practice of psychiatry in the US and UK in ways that locate them at different points along this continuum. In America mental illnesses are seen as biologically based brain disorders, whose appropriate treatment is with medication. So they would sit at the left of the continuum. In the UK, psychiatric practice pays more attention to the effects of trauma, and as well as medication uses talking therapies to help patients make sense of their experience. So they would sit at about the middle.

Where Australian mental health services sit on this continuum is not clear. In Australian mental health policy conditions such as schizophrenia are characterised as diseases of the brain, for which the primary mode of treatment is medication. Patients attending publicly funded services are unlikely to be offered talking therapies. At the same time, policy is framed in the language of ‘recovery’, and reflects the ideals of autonomy and independence espoused by the consumer / survivor movement (Australian Government Department of Health and Ageing 2008; Victorian Department of Human Services 2009; Meadows et al 2007). Some funded services offer Hearing Voices groups that explore meaning and strategies, and promote peer support (Voices Vic 2009). In addition, Australia is distinctive in funding an array of non-clinical support services for people diagnosed with schizophrenia. Delivered by non-government agencies, these services are known by different names in different states: in Victoria, where they have been established the longest, they are called psychiatric disability rehabilitation support, or PDRS (Clear 2007).

One consequence of a policy focus on partnership and collaboration is that Australian mental health services embrace a variety of ways of thinking about the things their clients experience. While individual practitioners in each discipline or service type may be
located at various points along the continuum, a broad characterisation would show
psychiatry and clinical services as located at the left, with some ‘progressive’ voices
tending toward the centre. The position of non-clinical services that provide rehabilitation
support is more ambiguous. These services accept a medical view of schizophrenia as an
illness grounded in brain chemistry, a position located on the left side of the continuum.
At the same time, some are strongly influenced by views articulated by
consumer/survivor movement, a position located clearly to the right of centre. This
diversity in views between and within service sectors makes the mental health sector an
interesting place to work.

**Diversity in practice**

In Australia PDRS agencies operate at the frontline of debates around understandings of
mental illness. They work closely with, or under the direction of, clinical services; and
their ethos is informed to varying degrees by views arising from the consumer-survivor
movement. The diversity of views at play within the mental health service system is
illustrated by the positions taken by speakers at a conference convened in 2010 by the
PDRS peak agency VICSERV (www.vicserv.org.au).

Speakers at this conference occupied a wide range of positions on the continuum
described above. Here I give two examples, which I name (prosaically) as position one
and position two. These are not direct reflections of views articulated by specific
individuals: rather they are ideal types that illustrate positions represented by participants
who had profile as invited speakers. I describe them here to show how the views
articulated by speakers at this forum occupy very different locations on the continuum
described above.

Position one would map on our continuum about mid-way between left and centre.
Speakers at this position were typically associated with clinical services, located in
Australia. These speakers framed their arguments around the concept ‘mental ill health’.
They regarded early detection of and intervention in episodes of mental ill-health as
crucial. Some argued also that responses other than medication are important. In the context of medically-focused psychiatry, moving the focus of first response away from medication and clinical services toward a recognition of life context and other factors, can be seen as progressive; even revolutionary. The approach advocated by these speakers represents a significant shift from established practice.

In terms of our continuum, the revolution envisaged by these speakers is one that moves practice from the left side of the continuum, toward the centre. From a point of view within psychiatry, seeing this argument as progressive makes perfect sense. From the perspective I call position two, this argument looks quite different. In this view, framing distress in terms of mental ill-health has the unwelcome effect of expanding the reach of medical authority. It increases the range of human experience in which a doctor’s authority to define what’s going on is greater than that of the person experiencing it.

Position two maps mid-way between right and centre on our continuum, the mirror-image of the position occupied by position one. Speakers from this position came from a variety of disciplines, some clinical and some not. They were people prominent in the consumer/survivor movement, mostly from outside Australia, who attended the conference as invited speakers. The language used by these speakers differed from that used by speakers at position one. Where people speaking from position one talked about mental ill-health, those from position two talked about distress; and where position one talked about psychosis, position two talked about altered states. In relation to what position one would call symptoms, the attitude expressed by position two was, in the words of one speaker: ‘Welcome old friend. What have you come to teach me this time?’

The differences between these sets of views are more than cosmetic. For example, speakers at both positions talked about the importance of providing services to young people in schools, but the kinds of services they had in mind were quite different. In the vision articulated by position one, the aim of such intervention is to identify young people who are in the early stages of mental ill-health, and who may be at risk of
developing psychotic disorders. Those identified can then be referred to innovative models of delivery that are integrated with, if not branded as, clinical services. In contrast, the approach described by position two aims to engage young people in conversation about questions like: ‘What do you do if you’re getting bullied?’, ‘What do you do if you’re unhappy?’, and ‘How can we learn to treat each other better?’ Speakers from both positions seek to de-stigmatize the experience of mental distress, and to offer practical support. In language and assumptions their views are quite different. These differences lead to significant divergence in practice.

While this conference provided a forum for a range of voices to be heard, there was little dialogue between them. It is difficult to make sense of the differences between the views represented here, without spelling out the assumptions that inform them.

When we talk among our peers at a specialist conference we don’t usually make our assumptions explicit. To grasp them a listener would need to pay attention to language, and notice what a speaker takes for granted, what they regard as so obvious that it doesn’t need to be said. For people who are new to working in the mental health sector, and for service users and their families, this is not easy to do. (As part of my talk at this conference I sketched the continuum I’ve drawn here. The people who approached me afterward to say they had found it useful were all service users.)

The boundaries of credibility

The continuum described above also provides ways to think about first person accounts of madness. I illustrate this by considering several recently published accounts. (For an exhaustive bibliography of published first-person accounts see Hornstein 2008.)

The first sits to the left of the continuum. It is written by Elyn Saks, an American academic who was diagnosed with bipolar disorder. In her book, *The Center Cannot Hold* (2007), Saks accepts uncritically the view that her distressing experiences are the result of a biologically-based disorder of her brain, that must be treated with medication.
Saks offers no challenge to the interpretations proposed by her doctors. And unsurprisingly, her book is endorsed and praised by the American Psychiatric Association.

The next two accounts would be located to the right of Saks, but not quite so far as the middle. The memoir *Flying with Paper Wings* (2009) is written by Australian consumer advocate Sandy Jeffs. Jeffs offers a moving account of her young life, her diagnosis with schizophrenia and her subsequent experience as a patient of mental health services. She tells her story as having developed an illness that’s distressing and disabling, and argues that the treatment she received has in many ways served to increase both her disability and her distress. Jeffs doesn’t go so far as to propose that the content of her voices and intrusive ideas makes sense, and might be related to things that happened when she was young. Instead, she confines her critique to an argument that mental health services should be more responsive to concerns expressed by people being treated. A memoir by another Australian consumer advocate, Richard McLean, occupies a similar position to that of Jeffs. His book *Recovered not cured* (2003) was awarded ‘Book of the Year’ in 2003 by the advocacy organisation SANE (2009). Jeffs’ memoir is SANE ‘Book of the Year’ for 2010.

The final account sits at the right side of the continuum. Roy Vincent’s memoir, *Listening to the Silences* (2007) was first published online through the Hearing Voices Network when its author was 80 years of age. Vincent, an Englishman, argues that the voices and other perceptions that have plagued him over many years are not caused by illness, but are intrusions by spiritual entities that exist outside himself. His book describes the results of his attempts to investigate the phenomena, and the many strategies he has devised in order to cope with them.

The accounts created by Saks, Jeffs and McLean are located safely within the idea that what they experience is an illness that needs to be treated. And these accounts are endorsed by mental health industry bodies in the countries in which they were published.
In contrast, Vincent’s account rejects this framing. Although he writes at length about strategies he’s found to be effective in living with his intrusive perceptions, his work is not promoted by mental health services and I have never seen it cited.

The varying responses received by these accounts suggest that - at least in the view of industry or disciplinary bodies associated with mental health services - the boundaries of credibility coincide with ideas about illness and treatment. Authors whose work is awarded are those who may criticize some aspects of the care they have received, but do not question the idea that they have an illness that needs treatment. Accounts that repudiate the idea that their authors’ experiences are evidence of illness are less likely to be recognized as being of value (see Gosden 2001 for further discussion of this point). The idea that people who have experienced psychosis have an illness that needs treatment marks the point on the continuum at which views on one side can be regarded as credible participants in conversations about mental health and illness, while those on the other cannot.

**Invisible walls**

In Australia, disciplinary and service cultures are grounded in differing and unarticulated assumptions about the meaning of service users’ experience. These differences create barriers to communication between practitioners working in different service types. They also make it difficult for service users, carers and newcomers to the sector to make sense of what they hear. Unarticulated assumptions construct invisible walls, marking the boundaries that separate views that can be regarded as credible in conversations about mental health, from those that cannot. Thinking of views as falling along a continuum, with ideas about illness and treatment at one end and distress and support at the other, provides one way of making these assumptions visible.

Anyone with an interest in mental health services will know that the debates I have canvassed here are not new. But still, the diversity of practice in mental health services, and the ideas that inform them, remain bewildering to a newcomer. I offer the ideas
outlined in this paper as a map for the bewildered. I hope they can be ‘tools to think with, at least until we find something better’ (Smith 1990:206).

REFERENCES
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https://protected.accountsupport.com/mhpeer/trainings.html