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Professional education and Mad Studies: learning and teaching about service users' understandings of mental and emotional distress

Joanne Newman, Kathy Boxall, Rebecca Jury and Julie Dickinson

ABSTRACT

This paper considers the inclusion of mental health service users' experiences and perspectives in professional education classrooms. After brief introductions to the authors' backgrounds, the paper discusses professional expertise and knowledge and the accreditation of professional education courses. It then goes on to explore service users' understandings of mental and emotional distress and the development of Mad Studies which, at first sight, may appear incompatible with professional education courses. Discussion then turns to the development and trial of a living experience learning resource, which portrays the first author's knowledge and understanding of having voices. The paper concludes by arguing for the inclusion of Mad Studies knowledges in professional education classrooms.

POINTS OF INTEREST

1. This paper is about including mental health service users' experiences and knowledges in professional education classrooms.
2. The paper discusses service users' own understandings of mental and emotional distress and the international development of Mad Studies – cooperative study of mental health service users' experiential knowledges.
3. It also describes how we produced a learning resource (video film) which portrays the first author's understanding of having or hearing voices.
4. The learning resource was used in research with seven first year social work students and we found that the students' understandings of mental illness changed after viewing the resource.
5. Mad Studies offers mental health service users hope and the possibility of change. It is important therefore that Mad Studies knowledges are included in professional education.

Introduction

This paper explores the inclusion of living experiences of mental and emotional distress in professional education classrooms. Our discussion relates to professional education for a range of professions, including psychiatry, psychiatric nursing, psychology, social work and occupational therapy; but the focus of our paper is on social work education, as this is the area in which we have been working together. Historically, the social work profession was underpinned by biomedical understandings of health and illness and the knowledge taught on early courses of professional social work education in Australia placed strong emphasis on casework and psychoanalytic approaches (Napier and George, 2001; Mendes, 2005). Similar historical focus on biomedical understandings of mental health and illness was evident internationally in training for other mental health professions (Oliver and Barnes 2012; Mitchell, 2016). More recently, social work education has been broadened to embrace service user perspectives (Beresford and Boxall, 2013; Irvine et al, 2015) and there are parallel developments in education for other professions (HCPC, 2014; Happell et al, 2014). It is this development of the inclusion of service user perspectives in professional education in which we situate our discussion. We are interested in service users' perspectives as a source of knowledge – or knowledges – and the place that these knowledges may, or may not, have in the professional education classroom.

The paper also includes discussion of the development and trial of a mental health learning resource, which explores how the first author (Joanne) understands her experience of having voices. We use the term 'mental health service users/survivors' as a means of identifying people who are (or have been) on the receiving end of mental health services. The term 'lived experience' is often used to refer to subjective, first-hand, accounts of personal experience but we use the term '*living* experience' here to indicate experiences which are ongoing, rather than in the past. We refer to 'having voices', as this is how Joanne talks about her experience of voices and we use the term 'the academy' as a shorthand for universities and institutes of higher education.

The paper begins by providing background information about the authors and goes on to consider professional expertise, the dominance of biomedical understandings of mental illness, and accreditation processes for professional education. We also discuss the sharing

of service users' knowledges and understandings via the internet, and the development of Mad Studies. We then turn to discussion of the development and piloting of the learning resource at Edith Cowan University (ECU) and its implications for professional education more broadly. The paper concludes by arguing for the inclusion of Mad Studies knowledges and perspectives in professional education courses.

Backgrounds

In this section, we provide background information about the four authors of this paper and the perspectives and experiences we each bring. Historically, research about mental illness adopted a positivist (objective and distanced) approach to the people it studied (Boxall and Beresford, 2013; Beresford, 2003) and some contemporary research about mental illness continues to adopt a similar position (for example, McGorry, 2015; Widge et al, 2017). Our concern in this paper, however, is with subjective understandings of mental and emotional distress. None of the authors of this paper subscribe to a medical model of mental illness, which locates problems in biomedical deficits or disorders in the physiology of individuals, but for ease of reading, we have refrained from enclosing mental illness in 'scare quotes' each time we use the term.

Although we share similar understandings of the genesis of so-called mental illness, we have arrived at our understandings in different ways, as we explain below.

Joanne

I'm Joanne. I have voices. I have voices because of trauma. Trauma has been very present in my life – I experienced sexual abuse at ages three and eleven, and sexual assault at fifteen. I also had learning difficulties at school and when my family relocated from Geraldton to Perth (both in Western Australia), I was bullied every single day at my new primary school. Eventually, I was excluded from everyday activities. At high school I experienced more of the same. My differences were emerging now, including sexual orientation, and I became more marginalised and excluded. I left school and had periods of employment and unemployment. Then a social worker found me sheltered employment, where I experienced more abuse and ended up going mad. My madness progressed through going to my GP, to seeing a

psychiatrist, to admission to psychiatric hospital, medication and acquired mental illness diagnoses. I found it difficult to cope with the unwanted effects of medication but later went to a day hospital where I received good and useful help; but eventually I was put on the scrap heap. I felt abandoned by society because I was given the invalidity pension for life. I was IN-VALID.

Later, I met my now former partner, disclosed trauma and was believed. I then had years of re-traumatising therapy before meeting my current therapist Julie in 2009. Julie is a remarkable social worker and narrative therapist. Julie often held hope when I had little myself. Eventually I came out to Julie about having voices and was surprised when she spoke to my voices. My healing journey really began with Julie and I started living my life. I also received invaluable support from Richmond Wellbeing in Perth and from Lyn Mahboub, who was the first person I met with lived experienced of having voices. Lyn inspired me to learn more about the Hearing Voices movement and, with Lanie Pianta, I started a group for people who have/hear voices – Hearing Voices Busselton. I have also presented at local groups and organisations, Edith Cowan University, Curtin University and mental health and social work conferences. I am active on social media and am a Moderator for the *Drop the Disorder!* Facebook page. The internet and social media have been really important in my journey as they have enabled me to connect with a worldwide community of mental health services users/survivors and share our own understandings of madness and distress.

Today, I have four voices. I think of them as a cheer squad who guide, support and protect me; *they look out for me* and give me some really great tips (especially when I'm writing poetry). I am awakening to life.

Kathy

I'm a survivor of the British psychiatric system. In my early twenties, my life was dominated by psychiatry and I was told that I was a 'very seriously mentally sick young woman' who would need to take medication for the 'rest of my life'. I was also instructed to avoid studying or stressful occupations and told that the best I

could hope for would be to work in a bookshop – if I worked at all. The first time I was admitted to hospital I was in my final year at university where, as a physics student, I'd had rigorous training in the scientific method and the importance of justifying knowledge claims. I knew there were no laboratory tests for mental illness, so I couldn't understand how the psychiatrists could *know* with such certainty that I was mentally ill. What was clear however was that I was in a situation of no hope. I was repeatedly told that I needed to accept that I was mentally ill (and would be for the rest of my life) and let go of any future plans or aspirations. Despite these dire predictions, I eventually got a job working in a children's home and later trained and practised as a social worker. Although outwardly successful, I continued to worry about the professionals' prognoses on an almost daily basis and their predictions served as my constant companion at night, as I struggled to sleep. In 2004, twenty years after my last contact with the psychiatric system, I was awarded a PhD for a thesis which explored service users' knowledges; and ten years later, I came to Australia to take up a post as Professor of Social Work and Disability Studies at Edith Cowan University (ECU) in Bunbury, Western Australia.

Rebecca

I am a social worker and an academic. My key area of focus for teaching and research is service user involvement in social work practice, policy, research and education. I have been interested in service user expertise and knowledges for many years and this interest stemmed from my observations of a family member's resistance to traditional medical approaches to "treating" mental health issues and alternate, self-led approaches to maintaining wellbeing. This has led me to question the interactions between professional and living experience knowledges and I have pursued these ideas within my teaching in social work and through engagement in qualitative research approaches.

Julie

I have worked in the field of Mental Health as a Social Worker, since 1960. I have always remained concerned and questioning of the diagnosis of mental health and the system in which it is treated. I also taught at Curtin University for 15 years and

am involved in casual work at the School of Medical and Health Sciences at ECU. I also continue to have a small Private Practice. My training in Narrative Therapy at the Dulwich Centre (Adelaide, South Australia), which commenced in 1998, changed my way of working and teaching. It has led to an emphasis on being free of preconceived 'truths' and considering the person coming for assistance to be the expert on their own life. This has required me to listen at a deeper level and to continually check with the visiting person, that our work is relevant and of use to the goals they wish to attain. My part in the learning resource film led to my continued attempt to further understand the experience of hearing voices.

While the four of us, as individuals, reject biomedical understandings of mental illness, it is important to acknowledge that we live and work in a world where biomedical understandings dominate (Rogers and Pilgrim, 2014; Mitchell, 2016). In light of this, in addition to highlighting service users' knowledges and Mad Studies, this paper also includes discussion of dominant understandings of mental illness.

Professional expertise

People diagnosed as mentally ill come into contact with a range of different professional groups including psychiatrists, psychologists, nurses, social workers and occupational therapists. Each of these professions claim to have specialist knowledge and skill in a particular aspect of the treatment or support of mental health service users. The academy plays a key role in the education of new members of these professions who, on qualifying, are licensed to employ the 'dividing practices' of their profession (Foucault, 1982; Boxall and Beresford, 2016). As David Mitchell (2016, p10) explains, professional education enables graduates, 'to achieve a standard of living while touting degrees of heteronormativity that distance some bodies (the diagnosees) from membership in the human community while supporting others (the diagnosers) as embodying its essence'. With the exception of psychiatrists and psychologists, most professionals working in the mental health field do not formally diagnose people as mentally ill; though their observations and assessments often contribute to formal diagnostic processes. In this paper, we are particularly concerned with the social work profession, which aims to promote 'social change and development, social cohesion, and the empowerment and liberation of people' (IFSW/IASSW, 2014). The extent

to which social work education should support or challenge psychiatric diagnosis is open to question and varies in different contexts (Gambrill, 2014). For example, in the USA, social work students 'are taught how to diagnose using the DSM-5 [APA 2013]'; something which Carol Tosone (2016, p.109) notes may be in direct conflict with the profession's commitment to strengths-based assessment.

In addition to contributing to diagnostic processes, mental health professionals can also have considerable influence over the lives of service users, including prescribing psychiatric medication or, with legislative support, implementing coercive treatment regimens in hospitals or community settings (Light et al, 2017). The professionals' authority to intervene in the lives of service users derives from their claim to exclusive knowledge and expertise in the needs and interests of those who use or receive their services. Because of this expertise, and also the ethical code of their profession, professionals argue that they are in a better position than their clients to define what is in the clients' best interest (Wilding, 1982; Hugman, 1991; Stanley, 2016). Professional expertise is also the dominant model of underpinning knowledge for courses of professional education (Schön, 1984; Dustin, 2007). Academic and professional knowledge about mental illness has claimed neutrality and objectivity in its study; a claim which has resulted in deeply discrediting and discarding the knowledges of mental health service users/survivors themselves (LeFrançois et al, 2013; 2016; Russo and Sweeney, 2016; Ingram, 2016). This paper seeks to challenge the dominance of professional expertise and to argue that service users' and survivors' perspectives should be valued as sources of knowledge in professional education classrooms.

Internet knowledges

Richard and Daniel Susskind (2015) note that 98 percent of the world's stored information has already been digitised, including the specialist knowledge of the professions. Susskind and Susskind (2015, p211) argue that, 'when knowledge is digitized, it can be liberated' and, although some of this knowledge has to be purchased in the form of e-books or electronic journal papers, much of it is available free of charge. Research funding bodies also increasingly require findings from research to be published in open access journals, or placed in institutional repositories (Wahid and Mat, 2016), which means the findings are

freely available to anyone with access to the internet. Knowledge, including underpinning knowledge for the professions, is becoming increasingly accessible to those who are prepared to search for it. As a result, the professions' claims to *exclusive* knowledge and expertise are being eroded, with potential for subsequent erosion of their power (Keen, 2011). For mental health service users, however, the power relationship between professional and service user is likely to endure because of the legislative powers invested in some mental health professionals to impose psychiatric treatment against the will of the recipient (Wilson and Beresford, 2000; Beresford and Boxall, 2012).

The internet also increasingly contains mental health service users'/survivors' own understandings and analyses of their lives and experiences. Published analyses from people who have been on the receiving end of mental health services have been available for many years. These have tended to highlight imposed, rather than negotiated, understandings of mental and emotional distress, and violations of service users' human rights (for example: Chamberlin, 1988; O'Hagan, 1993; Pembroke, 1994; Campbell 2005). The development of the internet has enabled these resources to be shared much more readily and has also contributed to the further development of international networks of mental health service users, consumers, survivors and ex-patients (for example, *Mind Freedom International*, *European Network of Users and Survivors of Psychiatry*, *World Network of Users and Survivors of Psychiatry*). As a result, mental health service users and their organisations have been able to share information across the globe, garnering strength for their own understandings of mental and emotional distress and their own analyses of mental health policy and practice (Faulkner, 2017; Rose, 2017). One such development (which grew out of a collaboration in the 1980s between Dutch psychiatrist Marius Romme, researcher Sandra Escher, and voice-hearer Patsy Hage) is the Hearing Voices movement, an international collaboration of people who hear voices (Corstens et al, 2014). The understandings and analyses of people who have been on the receiving end of psychiatry are also being shared widely via Facebook groups including *Drop the Disorder!* whose 8,700+ international membership consists of mental health service users/survivors, supportive professionals, parents, family members, and interested members of the public. Websites critiquing dominant biomedical understandings of mental and emotional distress have also been

developed by professional allies – for example, journalist Robert Whitaker’s website *Mad in America*, and psychiatrist Peter Breggin’s website *Psychiatric Drug Facts*.

Historically, many social workers working in hospitals and mental health settings have supported the psychiatric profession’s assertion that people diagnosed with major mental illness need to be permanently medicated (Heimler, 1967; Margolin, 1997; Gambrill, 2012). However, with awareness of the long term adverse effects of psychiatric medication gaining greater visibility (Gøtzsche, Young and Crace, 2015; Dorozenko and Martin, 2017), mental health service users/survivors and their allies (including mental health professionals who are also allies) are now using the internet to offer advice and support to people who wish to withdraw from prescribed medication. For example, *Inner Compass Initiative* (www.theinnercompass.org), *Coming Off Psychiatric Medication* (comingoff.com), the *International Institute for Psychiatric Drug Withdrawal* (iipdw.com) and the *Let’s talk Withdrawal Podcast* Facebook group. The accessibility of these websites and support groups may present problems for social workers and other mental health professionals working within a conservative biomedical paradigm. They also raise questions for professional education and the extent to which it can – *or should* – support dominant biomedical understandings of mental illness and professional expertise; or mental health service users’ self-knowledge and self-determination. Given that critiques of biomedical approaches are also increasingly being voiced from more conventional arenas, discussion of this issue is now overdue. For example, a recent UN report on physical and mental health is unequivocally critical of current biomedical approaches to mental health:

A growing research base has produced evidence indicating that the status quo, preoccupied with biomedical interventions, including psychotropic medications and non-consensual measures, is no longer defensible in the context of improving mental health. Most important have been the organized efforts of civil society, particularly movements led by users and former users of mental health services and organizations of persons with disabilities, in calling attention to the failures of traditional mental health services to meet their needs and secure their rights (UN, 2017, p.4).

Accreditation of professional education

Accreditation standards lay down the priorities of professional curricula and courses are reviewed regularly by the relevant profession's accrediting body to ensure they continue to meet those standards. Professional accreditation therefore has considerable influence over the content and delivery of courses and has been variously described as 'serving a public good' (Universities Australia and Professions Australia, 2016, p3), protecting the public interest, serving the self-interest of the profession, or 'a shift in power from educators to managers and bureaucrats' (Harvey, 2004, p222). Accrediting bodies can also influence the way in which the contribution of service users is valued in courses of professional education. In the UK, service user involvement in social work education has been a requirement of course accreditation since 2003 when higher education institutions were required to involve service users and carers in all aspects of the qualifying level social work degree (DH, 2002, p9). Since then, the Health and Care Professions Council (HCPC), which regulates health and social care professions in the UK, has issued new guidance for education providers which similarly states that service users must be involved in courses of professional education (HCPC, 2014). The underpinning knowledge taught on courses of education for these professions is not regulated by the HCPC, the assumption being that teaching students about knowledge for professional practice is the remit of a profession's academics, rather than its service users; though there may of course be overlaps between the two groups, with service user academics now working in a number of universities internationally (Beresford and Boxall, 2012; Happell, et al 2015).

In Australia, where research for this paper took place, *The Roadmap for National Mental Health Reform 2012-2022* (COAG 2012), sets out the policy direction for all Australian governments in relation to mental health, advocating 'a person-centred, recovery-oriented approach' to mental health policy and practice (p14). Recovery has however been criticised because of its neoliberal agenda and focus on the individual, which may serve to mask broader social, economic and political determinants of health (Harper and Speed, 2012; Price-Robertson et al, 2017). In addition, as Joanne explains below, the concept of recovery can itself be unhelpful:

If we are talking about recovery in a mental health context, then I struggle because I personally don't accept the concept of 'mental illness'. If I don't believe in the concept of 'mental illness', how can I relate to recovery?

The COAG roadmap is clear that 'policy should be guided by, and respond to, people's lived experience' and that this requires cooperation with service users and carers in all areas of health care (COAG, 2012, p3). Brenda Happell and colleagues (2015) argue that this requirement for user involvement also extends to the education of health professionals. In relation to social work education, the Australian Social Work Education and Accreditation Standards (AASW, 2015) do not require education providers to involve service users. Despite this lack of mandate, there is evidence of innovative service user involvement in social work education in Australia; for example, Dorozenko, Ridley, Martin and Mahboub (2016).

Understandings of mental illness

Biological explanations for mental illness gained in strength from the 1980s and arose from concerns that psychiatry was being derided as a 'pseudoscience' because it lacked credibility when compared with other branches of medicine. Scientific approaches to the study of diagnostic criteria for mental illness provided the credibility that psychiatry was seeking and developments such as the Diagnostic and Statistical Manual of Mental Disorders (APA, 2013) led to large numbers of people across the globe being identified as mentally unwell (Karp and Birk, 2013). The recent 'neuro-turn' in psychiatry is viewed by many as providing further credibility for medicalised understandings of mental illness, with neuroimaging providing compelling visible evidence of anomaly in the 'mentally disordered brain' (Schultz 2016). This neuro-turn has also been heavily critiqued for lacking a robust research foundation, misleading the public about scientific certainties and masking social causes of mental distress such as poverty and discrimination (Schultz, 2016; Wastell and White, 2017). Nevertheless, biologically-based explanations for mental illness continue to dominate and are also endorsed by pharmaceutical companies promoting chemical interventions for mental ill-health (Karp and Birk, 2013; Davies, 2017); biological explanations also have widespread credence amongst the general public (Gambrill, 2012; Brinkmann, 2016).

There are however multiple ways of understanding and explaining mental and emotional distress (Rogers and Pilgrim, 2014) and Allan Horwitz (2013) discusses a range of sociological approaches. For example, the aetiological approach explores social causes for the symptoms of mental illness but does not question the existence of mental illness itself. Other approaches, which again do not challenge the existence of mental illness, study social responses to diagnosed mental illness symptoms. Social constructionist approaches, on the other hand, are concerned with how culture produces social expressions of mental illness and it is within this paradigm that many service users' understandings of their own experiences of mental and emotional distress lie (for example, Chamberlin, 1988; O'Hagan, 1993; Pembroke, 1994; Campbell, 2005; Longden, 2010). For many mental health service users/survivors, it is coming together with others who have survived the psychiatric system that validates their own understandings of mental and emotional distress. These activist groups are not a new development, with some having being formed more than sixty years ago; for example, the 1940s US group We Are Not Alone (Costa 2014); the 1960s US Mental Patients' Liberation groups (Chamberlin, 1988); the 1970s UK Mental Patients' Union branches (Campbell, 2005); and the 1970s Campaign Against Psychiatric Injustice in Australia (Epstein, 2013). The consciousness-raising or 'conscientisation' (Freire, 2005) role of these groups relied on members sharing their experiences and validating each other's understandings and reality.

Reflecting on her experiences of hospitalisation in the United States of America in the 1960s, Judi Chamberlin wrote:

I had never thought of myself as a particularly strong person, but after hospitalisation, I was convinced of my own worthlessness. [...] I had to fight the crippling belief in my inferiority, a belief I had been given by the people I once trusted as healers. It was years before I allowed myself to feel anger at a system that had locked me up, denied me warm meaningful contact with other human beings, drugged me, and so thoroughly confused me that I thought of this treatment as helpful. Of enormous help in digging through the layers of mystification has been my involvement, for the past six years, in a number of mental patients' liberation

groups, in which ex-patients have come together to validate our own pain and anger. (Chamberlin, 1977, p5).

Mary O'Hagan, who was hospitalised in New Zealand, wrote:

They told me gravely that I would have mood swings for the rest of my life, and that drugs were the only things that could help me. I passively accepted their verdict for a marginal life and it took me years to question their self-appointed monopoly on competence and insight. They kept my personal myths stuffed down my well. I suspect that much of the meaning in my madness still waits there, unravelled, in tight expectant bundles (O'Hagan, 1993, p1).

Eleanor Longden, who is part of the Hearing Voices Network, has written about her experiences of voice hearing:

Because everyone responded so negatively to the first voice I heard I learned not to trust my voices. If I'd never entered the psychiatric system things would have been very different for me. This is what has given me this imperative to go back into the system and try and make a difference. I think that the ownership of psychosis belongs to those that experience it. Psychiatry has to accept that. The question shouldn't be 'what's WRONG with you', rather than 'what's HAPPENED to you' (Longden, 2010, p258).

Before the internet, it was difficult for lone mental health service users to access views such as those above, or to resist dominant illness-based understandings of themselves (Wilson and Beresford, 2000). It is now much easier to find information and to identify groups of likeminded people who reject biomedical understandings of mental and emotional distress. Here, Joanne talks about her experience of using the internet to connect with people who hear voices and how her own understanding of her experiences has been reinforced through contact with other voice hearers.

Over the last two or three years, learning about Hearing Voices groups and reading literature and stuff, it's been an enormous learning curve. It's been like being in an elevator and going from the first floor to the hundredth, really, really quickly in one of those express lifts that go really fast! So, at times, it's been overwhelming and sometimes it's been, 'Ah gosh, Can I do this sort of thing?'

It was only three years ago that I first heard of Hearing Voices groups from my therapist, Julie, and I Googled it. I wanted to read everything I could and I guess that's why I found social media so important, like Facebook, because it connected me with other voice hearers around the world. That was really important to me, finding out that there were other voice hearers that I looked up to and thought, 'Oh Wow!' And these people were training and going to universities and doing their PhDs! And, for all sorts of reasons, I thought 'I can't do that'. But then I met Eleanor Longden and went to training with Rufus May and I felt that *my understanding of having voices* was validated.

Even though all of that's happened in the last three years, I think I'd already found my own understanding way back even when I was first in hospital and I came to this thought, 'Well maybe this is all happening because at the age of 15 something happened.' When I tried to tell the psychiatrists they said, 'Oh perhaps you did something,' and I shut up because I felt I was being blamed. Way back then, I came to this understanding that maybe this is all happening to me because this happened when I was 15, and because I was bullied at school. I started to think about it then. So that's 30 something years ago.

Mad Studies

In recent years, the internet has also facilitated the development of *Mad Studies*: co-operative study, on an international scale, of the experiential knowledges of mental health service users and survivors (Costa 2014; Beresford 2016; Ingram, 2016; LeFrancois et al, 2013; 2016; Beresford and Russo, 2016). Mad Studies has not developed in isolation, but builds on the work of mental health activists from the 1960s (for example, Chamberlin, 1988; Campbell, 2005; Epstein, 2013). Although not everyone is comfortable with the term

'mad', Peter Beresford argues that Mad Studies offers a powerful new alternative to conventional understandings of mental illness because it:

- has been grown with survivor involvement;
- is truly international;
- is flourishing and developing;
- is unequivocally non-medical, taking account of the social and the personal and psychological, as well as their relations with each other; and
- makes possible powerful alliances, crucially starting with survivors, survivor knowledges and research (Beresford, 2016, p352).

The commitment of Mad Studies to prioritising service user and survivor knowledges and to understanding mental and emotional distress from non-medical perspectives can be viewed as the antithesis of the dividing practices and heteronormative approaches to professional education, we refer to earlier in this paper (Foucault 1982; Mitchell 2016; Boxall and Beresford, 2016). This raised questions for us about where the experiential knowledges of mental health service users/survivors sit in relation to professional education, and was something we wanted to explore in our research.

Beresford argues that Mad Studies is likely to be helpful as long as it:

- is led by us and our experiential knowledge as survivors;
- engages committed allies; and
- is demedicalised and based on a social approach (Beresford, 2016, p352).

The development of the living experience learning resource and the research with social work students that we discuss in this paper followed these three precepts.

Development of the learning resource

Funding was received from Edith Cowan University to create a mental health learning resource for use with social work students and Joanne was employed to work on the

development and production of the resource. We also commissioned Kick the Dog film company to produce the resource professionally, under Joanne's direction. Our aim was to capture the richness of Joanne's story, as well as the presence of voices. We also wanted to provide a forum for Joanne to convey her own ideas and understandings about her experiences.

In Disability Studies, Colin Barnes has cautioned against disabled people telling their own individual stories, as this can serve to perpetuate negative stereotypes and 'detract attention away from the material and cultural forces which compound disabled people's disadvantage' (Barnes 1998, p77). More recently, in relation to Mad Studies, Lucy Costa (2014, n.p.) argues against 'sending consumer/survivors off by themselves so that they can tell their individual story or become a token poster child in projects with complex, deeply entrenched structural problems'. So why did we develop a learning resource in which Joanne tells her own story? There are two important reasons for this. The first is that in the early days of the disabled people's movement, people became aware of their collective experience of disability through the sharing of individual stories (Campbell and Oliver, 1996). Mad Studies is a relatively new development – both inside and outside the academy. At this early stage, the process of consciousness-raising, or conscientisation through the telling of individual stories, is an important part of the development of Mad Studies (Freire, 2005; Beresford and Russo, 2016). Students on courses of professional education may themselves be mental health service users/survivors and conscientisation can also take place in professional education classrooms (Beresford and Boxall, 2012; Boxall and Beresford, 2016). The second is that Joanne's story is not told in isolation. As explained earlier in this paper, Joanne is connected – via the internet – to a worldwide community of mental health service users/survivors and draws on their collective understandings of madness and distress when making sense of her own experiences.

The use of a video film format enabled us to portray Joanne's experience of having voices and also provided a window onto the usually private space of the therapy room, where Joanne talks to her therapist about her relationship with the voices and the meanings they have for her. Because the learning resource was to focus on Joanne's experiences, all of us were clear that Joanne should have ownership and control over both the production of the

resource, and the final product. Here, Joanne describes her experience of planning and filming the learning resource:

The timeframe was quite rapid – five months from conception to completion. I was given primary responsibility for sharing my experience in a process of co-production with a range of people: this included involvement in the decision about which film production company to hire and consultation with the owner/director of the company that was chosen. This was all new for me. I had never done anything like this before. The café scene was chosen after another more ambitious idea was discussed and set aside as it would be too difficult to film. My narrative therapist (Julie) and I consulted about the therapeutic conversation in great detail over several sessions. The conversation had to be with Julie because of our history, our established therapeutic relationship, trust, and safety. The filming took place over two days at two ECU campuses in Perth. The experience was both exhilarating and emotionally and psychologically exhausting for me. An experience I'll never forget.

Video scenes

This section outlines two of the scenes from the learning resource, both of which were used in the research with social work students. The café scene (2 minutes) was based on voices Joanne had experienced in similar situations – a script was written for this scene, which was acted for the film. The therapeutic conversation scene (23 minutes) was planned by Joanne and her therapist Julie and takes the form of an unscripted conversation between the two of them. To enable the reader to gain a sense of the content of the video scenes and their role in portraying and making sense of Joanne's voices, extracts from verbatim transcripts of the audio from these scenes are included below.

Café scene

In this scene, Joanne is meeting her friend in a café. As they sit down at a table together, Joanne has her back towards a man who is laughing and snorting as he speaks loudly to the man opposite him. Joanne and her friend greet each other and continue their conversation until Joanne stops talking and appears very distracted. Voice-over (VO)

comments – the voices of two people who are not present in the café – can then be heard.

VO CHILD VOICE: Oh, no, scary men, Joanne. Scary men. I'm scared. I want to run away.

VO SPIRITUAL MOTHER VOICE: Shh. Shh, little one. It's OK. It's OK. It'll be alright. Joanne will be alright. You will be, won't you, Joanne?

We then hear Joanne's voice as she responds to the child voice (but her lips do not move – the assumption being that all three of the voice-over voices, including her own, are in Joanne's head).

VO JOANNE: That's OK, little one. I'll be alright. And so will you. I'll sort it out. Thanks for looking out for me, though. I'll be safe.

Joanne's friend then asks if Joanne's OK, or if there's anything she wants and Joanne asks if they can go outside.

Therapeutic conversation scene

In this section of the resource, Joanne is filmed talking to her therapist Julie. The words in the verbatim transcript below are the words spoken by Joanne and Julie in the film (there are no voiceovers in this scene).

Julie begins by asking Joanne about her experience of hearing voices in the café that morning and Joanne responds:

JOANNE: It was quite noisy. There was, you know, a couple of guys straight behind me and they were really close. And... And when I sat down and we started talking, I...I heard my little child voice...

JULIE: Right.

JOANNE: And she was really afraid and...crying and quite upset. And...scared of the fact that there was men nearby. And consequently, you know, that always makes me feel quite distressed. You know, I've got a little kid really quite distressed in my head. So, um, yeah, it was really unpleasant. And I, I guess...although...my voices are supportive and kind mostly, well, all the time, I... That, yeah, that is really a difficult and distressing thing for me...

JULIE: To be close to men.

JOANNE: Yeah. And to have the voice, like, yeah.

JULIE: Right. Yes. Could you tell me just a little bit more about the voices and what they... You say there's more than one?

JOANNE: Yeah, yeah... There's, I've always had...three or four. And when I was about five or six, I can't remember, I first heard my, what I call my 'Spiritual Mother' voice. And that, that memory – because I don't really remember anything much before that, except for when I was three, when I was first abused, you know, sexually abused – and this one night, I just remember laying on my bed and it was like this overload of noise. Of voices that just sort of came, voices, like, from

everywhere. And it was like I was having a party in my head. And then, all of a sudden, that stopped. I mean, my mum came and checked on me. And said, you know, what was happening and went to see if I had a fever. But then that just stopped. And then the next thing I recall hearing is what I have said before, my Spiritual Mother voice just said, "Everything will be OK and I love you, Joanne." And, and then, probably not long after that, probably about, probably around the same time, I heard my little child voice as well.

JULIE: Right. Right. And are there just two? No, you said four, didn't you?

JOANNE: No. No, I've got four. One that's a teenage voice – her name, her name is actually Joy. And she came probably not long after I was, probably around when I was about 11, and not long after I had that experience, you know, that I've talked about before on Rottnest Island, with the man who sexually abused me, while I was on school camp over at Rottnest Island. And... And so I have Joy. And I have my spiritual mother voice. And I have the little child voice.

And then I also, about three or four years ago, got a new voice, Willow, who is really quite... the same as, a little bit sort of like, my spiritual mother voice, because they seem ageless. But my teenage voice, Joy, she's about 15 and she's always been almost like a supporter of mine.

Joanne and Julie's discussion continues in this scene for a total of 23 minutes, allowing the viewer to hear how Joanne herself makes sense of her voices through her discussion with her therapist.

When viewed as a whole, the resource conveys the meaning that the voices hold for Joanne and their place in her life is revealed through the different sections of the film, each of which can be viewed separately and incorporated into face-to-face or online teaching. The resource belongs to Joanne and she has chosen to make this freely available on You Tube for others to use (see YouTube video – *Who do you think I am?* <https://www.youtube.com/watch?v=3Z88xtFc9j0&t=308s>).

The research

Ethical approval was obtained from Edith Cowan University to study use of the learning resource with first year social work students who had not received previous teaching on mental health during the course. The aim of the research was to investigate how a living experience learning resource impacted on student learning about mental health. Our methodology was underpinned by social approaches to understanding mental and emotional distress and a commitment not to locate problems in individuals (Beresford, Nettle and Perring, 2010; Beresford, 2012). We invited first year Bachelor of Social Work students to participate in a single two-hour research session. Students were told that the research (held outside the teaching timetable) would follow the format of an ordinary teaching session, but with refreshments provided. They were also informed that, in addition to being asked to complete questionnaires, the research session would include audio-recordings of group discussions. We anticipated around 15 students would volunteer to attend the session – but in the event, only seven turned up. By chance, all of these were mature women students.

The research session was led by Joanne and Kathy – we introduced ourselves very briefly and did not disclose the more detailed information we provide at the beginning of this paper. Students were then given a unique ID and asked to complete a preliminary self-answer questionnaire which asked about: their understanding of mental illness; what they felt had influenced how they thought about mental illness; and the factors they thought could contribute to someone experiencing mental illness. They then viewed the *Café scene* and *Therapeutic conversation scene* and discussed these in small and large groups, with the large group discussion being audio-recorded. With access to their preliminary questionnaire, participants were then asked to complete a final questionnaire which asked if

anything during the research session had confirmed or changed their prior views about mental illness, and whether participating in the research session had opened up any new ideas for them. Finally, we came together for a whole group discussion, which was audio-recorded.

Three days after the research session, Jo and Kathy met to reflect on the experience of conducting the research and this discussion was also audio-recorded. All audio recordings were transcribed and the transcripts and questionnaires from the research session were analysed independently by Joanne and Kathy. We were looking for indications of whether or not students' views about mental illness had changed during the research session and our independent analyses of the data were remarkably similar.

Findings

When asked, in the preliminary questionnaire, to write a sentence or two about their understanding of mental illness, six of the seven students gave what could broadly be conceived as a biomedical response; for example:

To me mental illness is just like any other illness, but it affects your brain. (Student 02)

My understanding is that mental illness is a biological and/or genetic disposition coupled with life events, upsets, chemical balance. It is a chronic/acute medical condition such as diabetes. It can be curable. (Student 03)

Mental illness is a short, medium or long term condition experienced by person that requires managing and affects daily life. A range of factors including stress and genetics contribute to this. People from all walks of life and cultures are affected by this illness. (Student 05)

The language of 'mental illness' was used by students throughout the discussion of the café scene. None of them questioned this language, and the researchers had agreed beforehand not to challenge students' use of terminology (whatever terms they chose to use) during the

research session. Although some students had not been entirely clear about what was happening in the *Café scene* and understood Joanne's voices as a kind of 'inner dialogue', they were aware that she was experiencing distress. For example, the feedback from one small group was:

'We had something about the amount of physical activity as well as trying to cope with the mental exertion. If there's three people you're talking to at lunch, you can say, 'Hang on a second, I'm talking to someone else'. You know, you could implement that, but if you don't have the ability to quieten down one voice to listen to another voice there – I'm not sure whether you do or don't have that – but if everyone is just talking over the top of each other, then you're having to isolate those voices and deal with them as well as everything else.'

After viewing the *Therapeutic conversation scene* and discussing it in small groups, students were asked to complete the final questionnaire. This asked if participating in the research had opened up any new ideas for them. *All seven* of the respondents responded in the affirmative – for example:

Yes, trauma and the role it plays in hearing voices. And that sometimes people who hear voices don't want them to go, as they can have a positive impact on their lives. (Student 02)

I really enjoyed the opportunity to gain some personal perspective on what it is like to hear voices. I think I would have more confidence in speaking to someone about hearing voices. (Student 03)

Yes, it is new for me to consider the idea that people might want to keep their voices but after what Jo shares in the movie, it seems perfectly reasonable to me that a person (Jo, in this case) would be determined to see her voices as an effect of trauma, not as a symptom of mental illness. (Student 05)

When comparing the preliminary and final questionnaires, all of the students had moved away from dominant biomedical understandings of mental illness. Most students had understood the connection between trauma and hearing voices that Joanne had wanted to convey and their understanding of what might lead to mental illness appeared to have changed considerably in a short amount of time. Students' contributions to the final discussion also conveyed a depth and complexity to their newfound awareness, including the possibility that their changing ideas might not be acceptable in some workplaces, as this transcript illustrates (all contributions student voices, with most students participating in the discussion):

The divide is over whether you take a clinical approach, or a social-based approach.
.... The clinical system is very much medication.

That's the problem ... that normal everyday behaviours are put down to problems in the brain.

That's the thing though, the divide would be which area the professional is going to go into. If it's clinical then that's something that you'll just have to accept.

But wouldn't it be better to just take a bit from everything instead of being either or?

Depends on who you're working for – if you go to work for clinical, you have to abide by clinical regulations procedures and policies, so you don't get a choice.

You do, you do! [*several people speaking at once*]

You do, you get a choice if you want to apply to work there in the first place!

Yes, but if you're already working there, then that's what you have to fall under.

But there *is* one thing you can do. You can leave!

We had not expected students at the beginning of their social work course to have this level of awareness, but it is important to acknowledge the maturity and life-experience of the participants, all of whom were aged over 30 years.

Discussion

The findings of our research appear to indicate that all seven of the students changed their views about mental illness during the research session. It seems that the learning resource may have given students 'permission' to voice ideas that differ from dominant understandings of mental illness and their original ideas in the preliminary questionnaire; permission which was perhaps amplified by being delivered in a research setting, with the person who featured in the resource (Joanne) also being present in the room as a researcher. Another interpretation of the very marked shift in students' ideas away from dominant understandings is that students perhaps wanted to impress the researchers with their ability to learn.

It is important to note that the research was with a very small sample of mature women students who proved very receptive to learning about Joanne's understanding of having voices. As Mitchell (2016, p11) points out, the academy's 'manufacture' of 'professionals of normalization' is 'perhaps its most saleable commodity'. Professional associations and placement agencies also hold considerable sway over how students are taught about mental illness. Integrating Mad Studies into professional education could therefore present considerable challenges. That's not to deny however the impact of our small Mad Studies project on seven social work students and the researchers who worked on this project.

Joanne describes this impact from her perspective.

Doing research was a new thing for me. On the morning of the research, there was a bit of fear there because, for a long time, fear was a very dominant part of my life. Fear of lots of things, doing things, new things and also probably a lot of stuff to do with the past and people telling me that I wasn't good enough and I couldn't do this and couldn't do that. When the students arrived, I felt good (because they'd turned up!) But I was also feeling really apprehensive because I don't like looking at myself

on the screen, especially a big screen. In the discussion with the students, I was interested to hear what they thought of the film. A couple of people said the voices were like 'inner dialogue' – and I thought, 'Oh, did they get it? Did they know it was me having these experiences of having voices?' But at the end of the research, in the final question and answer session, it felt really good because the students said that their ideas had changed and that they'd really been challenged. And it was really good to read the difference in the questionnaires they filled in. I thought, 'How amazing is that?!' In the short time that we were there, doing that research, they saw my film and were able to reflect on it and come up with different ideas, even though they used the same language to express their new ideas. Every one of the questionnaires said they had changed their perception in some way and I thought to myself, at least seven people have had a chance to challenge their ideas around mental illness. It was exciting and, in a way, empowering and liberating to do something I never thought I'd be able to do.

Conclusion

There are multiple ways of understanding mental illness, including mental health service users' and survivors' own understandings of mental and emotional distress. Historically, the knowledge which underpins the mental health professions has been closely aligned to the academy and positivist approaches to research and knowledge production. Professional education aims to share this specialist knowledge with students, so that they too can claim the expertise of their chosen profession. However, because of the ready availability of internet knowledges, the professions' claims to exclusive knowledge can no longer be sustained. The continued dominance of professional expertise in Australian social work education, and in courses of professional education internationally, also raises questions about the sustainability of education for the professions.

A key innovation in recent years has been the development of Mad Studies and international collaborations of mental health service users and survivors, within – and beyond – the academy. The first author, Joanne, is connected to a global community of mental health activists via the internet and social media. The project described in this paper

sought to introduce students to a video learning resource which portrays Joanne's experiences of having voices and the ways in which she makes sense of those experiences. The learning resource was shared with first year social work students and their views about mental illness were captured using individual questionnaires and audio-recordings of group discussions.

Findings indicated that, for this small sample at least, students were open to challenging dominant ideas about mental illness and were receptive to new ways of understanding mental and emotional distress. They were also able to engage critically with their new knowledge, as the following extract illustrates:

[Student] I think there's also this idea that it's a pathology, having voices in your head. You said that you didn't want to lose them and that you would have felt lonely. I think there would be a pretty big perception around that the ultimate goal would be to relieve yourself of those voices. So, to accept them..... But then I suppose, you wouldn't necessarily want to keep bad voices that aren't supportive? Would you feel, or other people feel, the same about keeping voices that weren't so supportive?

[Joanne] And that's why I say you need to have a relationship with your voices. A lot of people in the Hearing Voices Movement understand that their voices may be the result of what happened to them, so you want a better understanding and a better relationship with the voices and to find out what those voices might be saying to you, you know, and to maybe change the relationship.

Whilst the objectives of conventional professional education and Mad Studies may appear to be at odds, our (albeit small) project indicates that they may not be entirely incompatible. The knowledges of Mad Studies can offer social work and other mental health professions an exciting new font of knowledge for professional education in the area of mental health. Most importantly, unlike conventional underpinning knowledge for professional education (which has emphasised pathology, disorder and permanence), Mad Studies offers mental health service users hope and the possibility of a positive future. Ethically, therefore, courses of professional education cannot afford to ignore the knowledges of Mad Studies.

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