I’ve had days when I’ve been quite psychotic. I struggle to work out which bits of my experience have actually happened. Everything feels dreamlike, and the dreams seem real. I try to implement my crisis relapse prevention plan: check out the evidence, ‘reality test’. I’m determined to hang on to my working life. I have two jobs: both involve working alongside psychologists as a coordinator of service-user and carer involvement, in the research department of a mental health trust and on the Doctoral Programme in Clinical Psychology at the Salomons Centre, Canterbury Christ Church University.

My psychotic blip keeps me off work for less than a week. When I go back, my head is hurting like a bit of me has been yanked in the wrong direction. I need to be there though: I like to earn money and enjoy the social aspect of being at work, but I’m also fascinated by what I do and believe strongly in its value. When we – people with lived experience – are able to speak up about experiences of mental health and neurological problems, it challenges ideas. Professionals may own the knowledge in this territory, but it is we ordinary and extraordinary people who can provide insight into the real-life experience.

Laura Lea with a day in the life of a service-user involvement coordinator

‘Psychology without compassion leaves an emptiness’

Bridging two worlds

Every time I use my key card in the morning I think: ‘Most other service users can’t get in this way. Should I be here?’ I feel like I’m not quite in the right place. I’ve got into the areas of the NHS and academia where psychologists are in their private territory. In this territory it’s unusual for people to identify as having a disability, or to acknowledge having used mental health or psychological services. I get a fairly unique view of services, research and the training of psychologists, from the inside out. I find myself in a bridging position between what often feels like two worlds: the one of the service user or research participant, and the one of the service provider or researcher.

From being on the inside I have found something out. There is really just one world. There are lots of psychologists who have their own psychological challenges, or have family members who do. We are all humans together. Yet somehow, the powerful knowledge systems in universities and mental health services work to reinforce old ideas of ‘them and us’.

My day at the university begins with emails. Sometimes these are to researchers, asking them to meet service users to explore their research idea. Always there are problems with psychologists’ diaries – and the service users or carers who get involved can also be busy. More than once a service user has said: ‘Do they think we sit around waiting for them...’
to ring us, like we have no other life? But I know, because it happened to me in the past, that when faced with psychological or neurological challenges, lives do shrink. We can literally be sitting there waiting for the phone to ring, hoping that we will somehow become connected to a wider world. One of the great pleasures of my work is that people can connect and reconnect. Psychologists and service users and carers together. Forging something new, enabling graduate and postgraduate learning and developing useful and sensitively delivered research.

Having set up some meetings, I speak to two of the service users I work with. They are new to the service-user group. My role is to help them manage the new environment; to ensure they feel supported and able to speak up. Faced with the power of psychological theory, language and practice, a very human reaction is to feel inadequate. Making sure meetings work for everyone takes robust thinking and careful facilitation. I have to address the principles, the purpose, the presence (i.e. people and how they are present), the processes and intended impact of any particular piece of work.

Being clear why we are meeting is the starting point… sometimes service users are not so sure why they are present. We can become the ‘token’ service user: only there as an example or specimen to be examined and demonstrated, rather than as a valued colleague who brings a different perspective, reflecting the richness of our own human story. Of course, these reflections may bring challenges. They might contradict the ideas of the psychologist. Even professionals are not immune from prejudice.

I spend the next hour looking at the comments from a colleague about a research paper we’re co-writing. It’s a piece about the proposed new mental health legislation, and it feels like my voice is being co-opted. I feel indignant, frustrated. How is it that psychologists earn a living from the experiences of those who are less well off? Why don’t we hear directly from the people concerned? How come we are talked about but not so often spoken with? It feels a fundamental injustice. Perhaps it was partly such ethical concerns that led the UK Health & Care Professions Council in their 2018 standard of education and training to require the involvement of service users and carers in the training of healthcare professionals.

My frustration leads to a stormy conversation with one of my psychologist colleagues. I tell him: ‘Own your own stuff and don’t try to own mine. Don’t take my words and shape them into something else… let my voice be heard.’ Or, as it’s said in the service-user movement, ‘Nothing about us without us’. These stories of living with psychological challenges are hard-won. They are the stories of suffering, making meanings out of this and – on a good day – finding the strength to say, ‘I am a survivor.’

**Not the whole story**

In 2016 the service-user group and colleagues at the university published a piece of research that had been long in the making. It asked the question: Why exactly are service users and carers willing to work with psychologists to educate them about the experience of living with a mental health diagnosis? The answer from our research was: Because we are interested in you, the psychologists, seeing us as human beings.

For me as someone who uses mental health services regularly, this is the most important thing. But I also want a psychologist to see me as unique. Because I have had psychosis, there are some who will make assumptions about me. These assumptions can make it difficult to see my value as a fully rounded human. I become a problem to be solved or researched. Yes, research does tell us important things. There are ‘facts’ about people with psychosis that it’s helpful for me to know. I need to know, for example, that social isolation tends to accompany psychosis. The psychologist practitioner needs to have this in their mind as they formulate. We need to understand that this is something to work against.

Being diagnosed means acquiring a label that is usually stigmatising and carries all sorts of negative implications; for instance, that you are dangerous. But it’s psychological knowledge that has prevented these labels sticking to me and in some way becoming my whole story. So I’m into the democratisation of psychological knowledge. It helps people take control. Facilitating conversations between service users, carers, researchers and clinicians helps that process of democratisation and humanising. I tell my story to make the claim to be more than a diagnosis and a problem. So do others. Through this process we hang on to our humanity and step aside from the diagnostic labels that can so easily be a way to devalue us.

But psychologists, like many academics and therapists, by and large hold their knowledge close to their chests. (There are notable exceptions, like Professor Tanya Byron.) One example of this is the new Power Threat Meaning Framework, advocating for formulation above diagnosis. It has had a mixed reaction from some psychologists, but what difference will it make to the ‘average’ patient, who will probably never hear of it? There is block in the pipeline between service users (and carers) and psychologists and the knowledge they hold. This is despite the valiant efforts of the British Psychological Society to provide accessible and robust information about psychological.
problems, including the report *Understanding Psychosis and Schizophrenia*.

Such frameworks are empowering for me, helping to make some meaning out of my experience. They acknowledge that often we can feel powerless in the face of discrimination, poverty and oppression. They ask us to think about our own relationship to power. I seem to have doggedly refused to hand over my power and personal agency. They’re top of my agenda. How to accept that power is limited, to find it, acknowledge it and increase it. This belief informs the way I work. I ask the question, ‘How can we hear the voice of the service users and carers?’ so this can inform the work of psychologists.

**The personal and professional**

At 11.30, after a walk to the coffee shop, I plan a teaching session involving people with lived experience of being sectioned under the Mental Health Act. I begin by asking the question, ‘Do the aims of people who use services, as represented by our lived-experience colleagues, align with the outcomes that the psychology lecturer has in mind?’ I make sure that differences between people are noticed. Understanding and even celebrating difference brings richer teaching, better research and a fuller life. It really isn’t about conformity. My life hasn’t conformed. My life plan went wrong, things happened that I didn’t bargain for. I didn’t want it to be like this. None of the service users or carers who take part in our research, or the teaching on the programme, wanted or expected their lives to be different or challenging. That doesn’t stop people judging them. The old-fashioned deficit approach, that sees people in contact with services as missing something normal and as a problem to be solved, is still to be found.

Getting busy and pounding on my keyboard helps me focus away from the impact of recently being unwell. I take time to think: How will I stay well? How much of my own lived experience should I bring to today’s work? This is not just a question for me, it’s a question that our trainee psychologists are facing too. Where exactly does the boundary between the personal and the professional lie? How much meaning and space should each of us give to our own personal struggles? In what ways should these inform the working lives of psychologists?

In the afternoon, I and a colleague present a teaching session entitled ‘What is psychosis?’. I want to share information about this unusual and altered state. I want to demystify it. I hope to help people become better friends, colleagues, therapists and researchers who will be more understanding and responsive. I tell the students about how bright everything becomes. I tell them that colours are stronger, that sounds are more intense, that touch, taste and smell are bigger and have more impact. I say I forget to drink or eat and that I can’t tell what time it is. I talk about the multiple connections that we all take for granted but are unaware of that exist below the conscious thresholds of lives. How these connections surface and how scary, frightening and bewildering this is. I talk about what helps. I also unashamedly plug the research topics I am interested in (service users should have a say in research too). Speaking my story takes an emotional toll; but the nuanced and positive view of my colleagues, and being with other people who have lived experience helps keep me well.

**Best and worst**

After the afternoon’s teaching I finish writing some words for an article and do some work on involving service users in the assessment of trainee psychologists. I spend time on the phone to a service user who is having doubts about staying with us in the involvement work. They are finding our systems too stressful, and the jump into the university too difficult to manage. I try to normalise this process, saying, ‘Just hold it lightly for the moment, things will fall into place if you stick with it.’ Then I speak to another colleague. We’re working on a research project developing a measure of the impact of involvement on mental health workers’ practice. I’m learning loads, including that factor analysis was first used on crops! Somehow, I think to myself, there may be trouble in using it on human behaviours. Human behaviour always comes with multiple meanings… yours and mine and half a dozen other people’s.

It’s tea time and I get to sit with the clinical academic tutors, all of whom are psychologists, and hear about their worlds. I feel accepted, but my difference as someone working out of the lived experience of mental health problems is acknowledged. Sometimes I grapple with this. I have been shaped by the best and worst aspects of psychology. I can improve from a psychotic experience within a week, because I borrow the knowledge held by social, positive and clinical psychologists. It allows me to navigate meanings about psychosis that are empowering rather than disempowering. But it’s not all roses. Some approaches to psychology have me pigeonholed as ‘abnormal’. I want to shout, ‘How dare you describe me in this way? What is normal anyway? Are you normal? None of us are.’

But I have learnt to avoid bitterness; to grow through suffering. We all need to meet the onslaught of negative narratives, wherever they come from, with some degree of compassion. Perhaps that’s what I want to communicate most in everything I do. Psychology without compassion leaves an emptiness.
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