"Are you experienced?" The use of experiential knowledge in mental health

Slide 2

I want to thank Lydia and Harry for their invitation to present here today. When I wrote the talk I had my experiences here last year very much at the forefront of my mind. In particular, two aspects of my trip last year stuck out. The first was my own position- I was here both as a mental health clinician/academic and a survivor of sexual abuse and therefore in some sense an 'expert by experience'. The second was something fellow delegates said towards the end of the conference. "What do we do now that we have talked about all these painful experiences that have happened to us?" "How do we leave here and go home with all these painful experiences aired but not resolved?" I thought this was a most profound and unsettling question. What are we doing when we bring our experience to a conference like this? What is our experience *for* here? What does experience mean?

Slide 3

The first thing I thought was it is not a therapeutic rendering of our experience for individual healing, or if we think it is this is understandable but we are liable to be disappointed. In my own psychological therapy I brought my 'experiences' of abuse and resultant trauma in order to first have them witnessed, then processed and then integrated. Of course, that is not what I thought was happening at the time. I went along desperate for help with a mess of experience that I did not understand or even see clearly.

So if the primary purpose of us discussing our 'experience' at a place like this is not psychologically therapeutic then is it communally therapeutic? By coming together in our varied roles can we find some common thread of humanity that can send us home feeling less alone? I think this is absolutely the case and I find working together with survivors of differing 'experiences' to be the most healing and gratifying aspects of my work as a survivor.

Slide 4

However, this again is not simple as any reading of the very real splits in mental health user movements will see that experiences are not shared across; as Jijian Veronka says in her skillful essay on the complexities of being a 'person with lived experience'; "Universalizing ourselves as 'experts by experience' belies the variances that our bodies carry, how we experience madness, and how mental health fields of power respond to us." So some people with 'lived experience' appreciate the validation and certainty of a diagnostic label, while others experience this categorization as a form of violence. Now the reasons for this are complex and as I argued in my talk last year may be as much down to the relational and ethical context in which the diagnosis occurs as anything else. Nonetheless we can see situations whereby people's 'lived experience' can be invalidated by the contradictory 'lived experience' of another person. Given the

emotional labour it takes to describe aspects of our 'experience' this invalidation is likely to be personally costly for many of us, it certainly has been for me.

So, given that there may be some risks entailed in acting as a 'person with lived experience', and given in a context like this one we might be unsure what this role allows us to do or to be. And given that it is highly likely that in having an homogenous term like 'person with lived experience' or 'expert by experience' to describe many of us we may actually mean very different things from one another, it seems useful to ask some questions about 'experience' in this context.

The development of what Professor of Citizen Participation Peter Beresford refers to as 'experiential knowledge' has come from the struggle of mental health service users over many decades to be recognized as having legitimate knowledge about the psychiatric system. More recently this struggle for both epistemic recognition and a demand for experiential knowledge to inform mental health research, policy and practice has been described under the umbrella term Mad Studies.

This struggle, that draws on civil rights movements both in terms of activist strategies and intellectual underpinning, has been in the face of a psychiatric orthodoxy that has viewed mental patients as lacking rationality. The fundamental 'irrationality' of the psychiatric patient is seen as reason in itself to discard any knowledge claims from them about their mental health and their treatment by the psychiatric system. The unseemly phrase 'the lunatics have taken over the asylum' makes clear this view on mad people actually being listened to.

Slide 5

(Aside)The phrase itself is of uncertain origin but is thought to be grounded in an 1845 Edgar Allen Poe short story called "The System of Dr Tarr and Professor Fether", where a new form of treatment is introduced known as the "system of soothing" in which patients are treated gently, their beliefs taken seriously and they are granted liberty as opposed to the norm of the time of punishment, accusations of lunacy and incarceration. A visitor who comes to the hospital is shocked and disappointed to find that the "system of soothing" has been abandoned on favour of a traditional, disciplinarian approach. Over the course of an increasingly bizarre dinner with a majority women staff, it becomes clear that the system of soothing has enabled the majority female patient body to take on the role of staff and to lock up the male staff as the newly anointed lunatics. One memorable phrase which makes clear the complexity of dividing lines between madness and sanity and the perverse logic of the psychiatric system is –

Slide 6

"If he (the lunatic) has a project in view, he conceals his design with a marvellous wisdom; and the dexterity with which he counterfeits sanity, presents, to the metaphysician, one of the most singular problems in the study of

mind. When a madman appears thoroughly sane, indeed, it is high time to put him in a straitjacket." The title of the story reveals to us what grizzly fate awaited the incarcerated staff at the hands of the recently liberated and vengeful patients- tarring and feathering. So while the story of origin for this phrase reveals an ironic and macabre morality play that teases with how difficult it is to tell apart the sane from the mad in appearance and action even back then, what we are left with is a seedy reductionism that renders mad knowledge dangerous.

What we see now in mental health services is in stark contrast to this, at least at the level of rhetoric. Policy abounds with regards to the value that 'experience' brings to the field of mental health. A few brief examples can illustrate a larger trend:

Slide 7

My own professional body the British Psychological Society has an Expert by Experience strategy 2018-2019 which describes EbyEs as; "service users, carers and members of the general public with direct or indirect experience of working with clinical psychologists, in a non-professional capacity." So in this case there is an emphasis not on the experiences that might bring us into contact with a psychologist in the first place but rather the experience of spending time with a psychologist in itself.

The NHS Care Quality Commission describes Experts by Experience similarly as "are people who have personal experience of using or caring for someone who uses health, mental health and/or social care services that we regulate."

Interestingly the Royal College of Psychiatry seem to have a more traditional, patient and carer involvement approach which does not grant any form of expertise to experience explicitly. This may reveal a more consumerist approach to involving service users which positions their views as important by virtue of their service use. Whether this reveals an ideological objection to the idea of mad peoples having expertise or their experience being important is a worthwhile question but one that would require a specific discourse analysis.

Slide 8

Closer to home the Mental Health Commission- A Vision of Recovery Model in Irish Mental Health Services states that "People who have recovered or are recovering from mental illness are very vital sources of knowledge about the recovery process. This is well recognised by organisations such as GROW and also Schizophrenia Ireland where people may describe themselves as gaining valuable knowledge about schizophrenia through *"self-experience*". (p13, italics added). This definition differs from the first two and is more like definitions from service users movements in that it sees expertise as not only being about service use but the importance of knowledge about mental health that develops from having an experience of a condition. So in my case according to this approach I have some claim to expertise by virtue of having 'experienced' a psychotic breakdown. So while in my capacity as an 'expert by experience' I may not take

over the asylum, I may at least be asked to assist in certain aspects of its administration.

Slide 9

Now as I said at the beginning much strong scholarly work has been done on how this identity of 'person with lived experience' offers opportunities to previously marginalised groups to change how mental health services are orgnaised. Jijian Veronka's paper 'On the dangers of strategic essentialism' offers a detailed and historically situated account of how this identity came to be in mental health, what it offers in way of opportunities but also importantly what risks it carries in reducing down the rich diversity of experience in mental health to an homogenous whole. Jijian cites at length a seminal paper in the area of experiential knowledge from a feminist historian perspective; Joan Scott's 1991 paper "The Evidence of Experience". In the paper, Scott emphasises the importance of 'visibility' in relation to the experiences of underground groups. She goes on to critique an ahistorical treatment of 'experience' as by necessity being framed within dominant discursive formations. A central passage that is troubling;

Slide 10

"It is not individuals who have experience, but subjects who are constituted through experience. Experience in this definition becomes not the origin of our explanation, not the authoritative evidence that grounds what is seen or known, but rather that which we seek to explain, that about which knowledge is produced. To think about experience in this way is to historicize it as well as to historicize the identities it produces." (p780).

But Scott's is only one, relatively recent take on 'experience' as an object or subject of enquiry. She is not the first to be tempted to do away with it as being too vague and broad, nor is she the first to want to critically examine its claim to represent a form of knowledge that can be trusted. And yet it seems to me that the underpinning philosophy driving Scott's paper- that of post-structuralism, or post-modernism, is one dominant way in which Mad Studies and academic work around 'experiential knowledge' understand what 'experience' means. And while Scott's work adds much to the field in questioning the essential truth claims that 'experiential knowledge' carries as a form of evidence in mental health, it would be limiting to solely focus on this particular understanding of what experience is and what it could be in mental health. Moreover, Scott's post-structuralist mistrust of experience being meaningful outside of discourse and historical context may have important implications for those of us using our experiences of mental health but take a different approach to understanding experience.

Slide 11

For the next section of my talk, I have drawn extensively on the work of the Intellectual Historian Martin Jay, in particular his 2005 book on the modern history of 'experience'- "Songs of Experience- Modern American and European

variations on a universal theme". In this book Jay charts the competing ways that 'experience' has been conceptualised from political, scientific, artistic, religious and philosophical perspectives. In this 'history of an idea' Jay discusses various attempts to reform or even to do away with the concept of experience altogether, the example of Joan Wallace Scott being one we have touched on. More than anything what becomes clear when we delve into the area of 'experience' as an idea is that there is no one formation of experience that can properly capture it's different uses across time and place. So we are not exploring 'experience' here in order to understand what it is, so much as thinking about it's different meanings in order to examine their usefulness in the development of experiential knowledge forms in the field of mental health.

What I want to consider with you today is a number of questions related to this: How is the history of experience as an idea relevant to those of us using our own experiences of mental health? How do we limit the range of ways we understand our experience by framing it in a particular way or for a particular purpose? What are some of the risks to us in using our experience to inform the field of mental health? How can we protect our 'experience' and the experience of others in doing this complex work?

Slide 12

Experience and science- "experience itself is a scientific scandal ... the ordinary everyday human world ... is consigned by science to its slop bucket." Laing, Voice of Experience (1982)

What RD Laing was voicing here, in his own inimitable style, is a longstanding and complex suspicion of experience as being an inferior form of knowledge than that gained through empirical investigation.

Slide 13

As the literary critic Terry Eagleton writes – We live in "the era of scientific rationalism, which is interested in weighing and measuring an object rather than registering its sinuous curve or peculiar tint. Science is the enemy of the sensuous. It is anchored in perception, but it also puts it into question. It looks as though the sun is coming up, but actually the earth is going down. A rift opens up between how things are and how we experience them. Since this is a rift inherent in reality itself, our experience of the world is bound to be a matter of misrecognition as well as knowledge."

I have highlighted the word misrecognition as we will return to it again later in our talk when we consider experience in the light of our current moment of identity politics.

In health research some researchers have welcomed the inclusion of experiential knowledge as a resource but only because it is 'wrong knowledge.' So in this case

you ask non-experts for information about a health condition in order to find out how lay people wrongly understand particular health problems.

This inherent suspicion of knowledge derived from experience has a long history, dating back to Francis Bacon, described by Hegel as the father of empiricism and who sought to develop reliable ways of measuring phenomena that has been called the 'quest for certainty'.

Slide 14

Bacon said "Experience is blind and silly, so that while men roam and wander around without any definitive course, merely taking counsel of things as happen to come before them, they range widely, yet move little forward." Reading this in Ireland I can't help but notice the reference to aimless wandering and two of the most important walks in all of literature, those of Steven Deadalus and Leopold Bloom in James Joyce's Ulysses. The initial spark of inspiration for which came from, of course, Joyce himself walking apparently aimlessly around Dublin. Now it seems to me that it is foolish to compare the wealth of knowledge about the human condition that can be learnt from a great work of art such as Ulysses and that which comes from systematic empirical scientific research. They are quite simply, different forms of knowledge.

Slide 15

The author and literary critic David Lodge talks about the potential complementary use of art and science by using examples from neuroscience and the idea of qualia. Qualia refers to individual subjective experience and Lodge points out that it highlights the limitations of science. While we can map which areas of the brain light up when a person eats an apple, we cannot capture scientifically the experience of eating an apple. Lodge proposes literature as a way to fill this empirical gap and uses the example of poetry as the purest, distilled form of qualia. I would suggest that experiential knowledge can be another way to do what empirical science alone cannot- to capture the qualia of living with mental health problems in all their multiplicity. In my own modest work I contributed an experience of living with trauma that tried to express something of what it was to be 'in it'. This required a departure from purely psychological models of explanation and led to me citing varying figures from the musician John Coltrane to the plays of Samuel Beckett to the Irish novelist Eimear McBride to try to get across what trauma is 'like'. It's flavor, texture, appearance and sound.

But we must not think of this work as directly comparable to empirical research and so downgrade it as a lesser form of knowledge as will inevitably happen if exposed to the same quality standards. It is simply different and necessary to reach the corners of madness that science cannot. Once we do this and do not make claims based on experiential knowledge that are similar to those from empirical research, then a lot of the historical tension between these two areas can disappear. It seems that in order for this to possible though, experiential knowledge must not be reduced down to a purely epistemological level- as in how reliable and valid is this knowledge form. This is as much an ethical demand

as a scientific one because it concerns the status of experiential knowledge as legitimate and therefore the standing of those with it as recognised epistemic subjects to use Miranda Fricker's phrase. So we can now turn to the ethical responsibilities of those of us who listen to and use the experiential knowledge of others in our work.

Responsible listeners- In her work on epistemic justice Fricker extends the scope to include the responsibilities of those witnessing experiential knowledge. Fricker calls for ethics to rescue epistemology from a moral relativism that cannot distinguish between good knowledge and bad. The seedy, bottom line argument that many of my colleagues in psychology espouse which claims that scientific knowledge is ethically neutral. We can see why psychology might like to claim moral neutrality from a cursory reading of its history, in particular Lynne Friedli's work on the use of psychology in welfare reform. Scientific objectivity in this case is a cover for psychological ideas being used to frighten many of our most marginalized, including many of my brothers and sisters from the survivor movement.

In evaluating the quality of experiential knowledge, Fricker warns against a reductionist binary choice between uncritical acceptance and intellectualist argumentation. Instead she calls for a 'critical openness' that is refined by the sensibility that can be offered by ethics.

Slide 16

This approach can promote certain ethical virtues including a testimonial sensibility which Fricker describes as "A testimonial sensibility, then, needs to be shaped by collective and individual experiences of testimonial encounters described in rich, socially specific terms relating to the trustworthiness of speakers of different social types in different sorts of contexts." She claims that the development of this sensibility can lead to an 'epistemic revolution' whereby our previously held beliefs about the trustworthiness of certain groups can be transformed. It is not difficult for us to conclude that an epistemic revolution rooted in an ethical sensibility is needed in mental health and that we as professional listeners have some way to go to achieve it. This critical openness does not require us to conclude that all experiential knowledge is true but instead that even if untrue, it is still important. I notice myself in my role as service user and carer involvement lead in my university (a job that is much more interesting than the title makes it sound), at times being ready to pass over experiential knowledge that does not fit with the university's agenda. Another thing I notice in my work in this area is that at times there is too much pain to bear in people's experience and so listeners turn away feeling overwhelmed and helpless. I think this is particularly true of trauma. If we think about the context of my abuse, it was the Christian Brothers who destroyed generations of young Irish men systematically through physical and sexual violence, and bullying. This all happened in plain sight. Our entire society turned a blind eye for decades. So part of the development of a testimonial sensibility has to be learning to bear difficult and distressing experiences in other people.

Being critically reflective to these tendencies to turn away or disregard is an

ethical task that requires vigilance. One way for me to create space for this vigilance is to come here and talk about it with you. Therefore this talk in itself can be seen as part of a process of me trying to develop a testimonial sensibility towards experiential knowledge. My point being that this is hard work and unlikely to come naturally to us. It requires commitment.

Now we have considered the ethical responsibilities of the listeners to experiential knowledge, we can return again finally to the purveyors of experiential knowledge. In this last section I want to consider with you what the risks are for those of us who use our experiential knowledge in the field of mental health, before concluding on how we might best navigate them individually and collectively.

Slide 17

Experience in an age of commodification risks jeopardizing an idealized version of our experiential knowledge through cheapening it to sell in the marketplace. As the German philosopher Theodor Adorno said in the 1990's, "The marrow of experience has been sucked out: there is none, not even that apparently set at remove from commerce, that has not been gnawed away." (1997, p31). In mental health we can see this in the work of Lucy Costa, Jijian Veronka and colleagues who has written about challenging the appropriation of psychiatric survivors experiential knowledge in the form of narratives. They talk about the risks of 'disability tourism' and 'patient porn' whereby the experiences of people can be coopted and used to progress the interests of mental health services. In the context of this paper we can think of this as the theft of experience. The use of experiential knowledge as a commodity, which can be traded in a marketplace, and discarded when no longer needed. And while I agree with Lucy and Jijian in this analysis, I think it could go further. I think that in an age of identity politics we can commodify our own experience in a way that can paradoxically lead to us being alienated from it in the way Adorno alluded to.

Slide 18

To turn back to Terry Eagleton again, "Instead of wandering along Hadrian's Wall, we have the Hadrian's Wall Experience; instead of the Giant's Causeway, the Giant's Causeway Experience….Since what all of these packaged tourist spots have in common is the fact that they are experienced, they become, like commodities, interchangeable. Experience, a term which can mean an event of exceptional value, ends up as a dead leveller."

In using experiential knowledge in mental health we can find ourselves inadvertently using some of our most painful memories as commodities. I think that a hardline identity politics pushes us towards what Martin Jay refers to as an 'overly claimed experience'. In other words experience that is too closely managed and presented. Experience that is used to say too clearly who we are and what we are not. Experience that binds us and limits us. The risks of misrecognition that we bookmarked earlier are heightened when we frame our experience and our identity in the same way. The costs for us having our experiential knowledge critiqued is much higher than when we place so much

value in it as part of who we are. I have been on the painful end of this myself, having 'debates' about aetiology in mental health which I am not able to approach as sport. As soon as someone questions the role of trauma in the development of mental health I cease to be a scientist. My survivor identity kicks in. I think this is where a lot of the pain in this experiential knowledge work can come from. When our experiential knowledge is not treated with sufficient respect then we feel it is an attack on our identity and draw battle lines accordingly. This can easily slip into a pattern of seeing our experiential knowledge as a source of group identity that clearly demarcates who we are in comparison to others and can lead to the sorts of splits that have bedevilled survivor movements for years. It also has the effect of limiting our exposure to different experiences, we can become stuck in the role of service user, survivor or expert by experience when that identity is no longer serving us. The risk for me is that in using my experiences of abuse to help inform the field of mental health, I become imprisoned by them once again.

So what is there to be done?

I think, for me at any rate, there is wisdom to be found in ideas and the idea of experience has been pored over for centuries in ways that I hope my talk has hinted at are not really that different from today in our relatively modest world of mental health.

Slide 19

To return to Martin Jay one more time, "the very notion of experience as a commodity for sale is precisely the opposite of what many…have argued an experience should be….*something which can never be fully possessed by its owner*. Instead because experiences involve encounters with otherness and open onto a future that is not fully contained in the past or the present, they defy the very attempt to reduce them to moments of fulfilled intensity in the marketplace of sensations." Jay (2005, p 405, italics added). Now one thing I think Jay is getting at here is that we can never really own our experiences and so experiential knowledge must be in constant movement, dynamic flux or else it ceases to be truly experiential at all. So in looking to a future not yet experienced, I try to ensure my experience of past traumas can be faithfully rendered in the present but not so much that they keep me stuck here.

Slide 20

As a final note I wanted to end on perhaps the greatest chronicler of experience, the poet and artist William Blake. In his poem Eternity he succinctly captures what I cannot about how to treat our own and others experiential knowledge:

"He who binds to himself a joy
Does the winged life destroy
He who kisses the joy as it flies
Lives in eternities sunrise"