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STUDIES SECTION

Lived Experience and the Limits (and Possibilities) of Empathy

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With increasing pressure to give voice to ‘lived experience’, the field of mental health needs methods for addressing subjective experience, especially that which is stigmatised or compromised by its labelling. Arts and humanities provide rich techniques for describing the texture and transmission of experience, and for theorising the emotional complexities of ‘knowledge exchange’. But do we have a disciplinary configuration up to the practical tasks of stigma reduction and empathy cultivation? For me, this is a pressing social challenge for Cultural Studies as an engaged, adaptive, post-disciplinary space, not only for thinking and analysis but for active intervention.

For much of my academic career I have focused on the communication of psychological trauma (especially through the arts) and on the possibilities of empathy, understood in terms of the capacity to receive, hear, understand and support such communicated distress. I locate this practice within an emergent, transdisciplinary cultural studies to the extent that it is concerned not only with art or psychology but with the effects of interactions between individuals within social and institutional settings. These interactions have an aesthetic dimension in the sense of the term referring to sensori-affective expression and perception, rather than to transactions in the realm of the arts. Aesthetic experience in this sense provides a vector for empathy and power relations at both micro and macro scale. The psychoanalyst Christopher Bollas makes use of the term ‘aesthetic’ to describe micro-interactions between a child and parent, for example¹ (Bollas, 1987); and the philosopher Jacques Ranciere describes how an aesthetic order constitutes the basis of social and political systems². Yet despite its influence in art and cultural studies Ranciere’s work has not yet inspired an empirical program. This in turn has led my colleagues and I to focus on the design and facilitation of ‘third space’ where arts, science and publics may intersect in ways that are not constrained by the goals of

established disciplines and practices, and where the politics of micro-interactions might be addressed in practical ways.³

To this end, in 2017 I launched *The Big Anxiety*, a mental health arts festival, designed to address key challenges in the mental health field by shifting the sphere of operations beyond the health sector. This shift does not mean abandoning the practical goals of improving mental health and wellbeing in favour of work that simply ‘represents’ or ‘exhibits’ in the manner expected of a gallery or museum; it entails using the cultural sector differently to undertake practical aesthetic work.⁴

Whilst mental health researchers make a genuine effort to enfranchise those we now call ‘consumers’, the field is largely dominated by a top-down medical model, within which knowledge translation is traditionally conceptualised in terms of a pipeline (getting the message out to would-be consumers). There are few specialised tools or techniques for bottom up research, or for cultivating emergent language (leaving aside for the moment the complex relationship of psychotherapy to the medical model). Yet the sector faces the challenge that some 65% of Australians with lived experience of mental health problems are not seeking help (far higher in certain populations). We propose that without richer methods of engagement and communication, this 65% can’t be reached. The festival’s goal is therefore to engage these ‘non-help seekers’ on new ground, creating settings or facilitating environments beyond the health sector that do not implicitly or explicitly define users as help-seekers. In other words, it starts from the practical reality that ‘non-help-seekers’, by virtue of keeping out of the sector, are not medical subjects and may even resist the pathologising of their distress or its labelling as a disorder.⁵ In many instances—particularly in the case of trauma and abuse—survivors are empowered by the more critical formulation that their symptoms and feelings are less a ‘disorder’ than a rationale response to disordered world.

Instead of signalling a health or medical focus, the festival tagline—arts + science + people—conveys a method rather than thematic. Grounded in lived experience and interactions with people and communities, the project harnesses capacity within the communications rich arts disciplines to develop engagement techniques. It also partners with mental health research institutes and NGOs, but rather than being a vehicle for delivery of evidence-based science, its exploratory collaborations aim to be evidence generating in their own right. The festival as a public facing engagement practice aligns with the research of the *feltExperience & Empathy Lab (fEEL)*, a transdisciplinary Lab funded by an ARC Laureate fellowship, the aim of which is similarly structural, bringing together arts, media, psychosocial and psychology researchers to work from and with lived experience.

In its first iteration *The Big Anxiety* was broad-ranging, encompassing diverse communities and sites across Greater Sydney, from a project focused on anxiety in Muslim communities associated with the Eid festival in Fairfield to collaborations with autistic young people to create spaces conducive to a ‘Neurodiverse City’. It has also begun to focus on continuity and support for participants, both within and either side of the festival. Rather than simply exhibiting the output of mental health projects or artworks that represent mental health, the festival is thus concerned with their conception, generation and practical use in ways that foreground relationships rather than outputs, and that imply a complex set of responsibilities. Whilst the festival’s projects are not therapeutic in a formal or programmatic sense, they create the potential for transformation, whether through reparative work, or promoting agency and options for actions.⁶

This is exemplified by one of the 2017 festival's main commissions, *Parragirls Past, Present* [PGH]—a collaboration with 'Parragirls' or former residents of the Parramatta Girls Home, a child welfare institution in Western Sydney (Kuchelmeister et al). As teenagers in the 1970s, the Parragirls were sent to PGH when the courts deemed them to be 'in moral danger' or neglect. The project was undertaken at the time of Royal Commission into Institutional Responses to Child Sexual Abuse, to which Parragirls were testifying.

The main output of this project is a 3D immersive film, narrated by Parragirls walking through the site. It took this form firstly because 3D capture was important to the goal of providing archival documentation of the site – including the so-called 'dungeon', the 'seg room', and the laundry where girls were tasked with scrubbing. It also creates an experience of being within and moving through the site. But its impact is perhaps greatest in terms of realising the subjective experience of institutionalisation. The immersive experience is brought to life by the women's soundtrack, recounting not only their time as residents but more recent interactions that compound their trauma. We hear, for example, of a visiting Family and Community Services (FACS) worker holding forth on the entrance steps, glibly reciting a non-factual history of Parramatta Girls. When Jenny McNally, one of the Parragirls narrating, challenged her account the FACS worker responds, 'and who are you?' Jenny recounts how she automatically said her name compliantly to this woman standing where the superintendent once stood, and in that moment was reduced to 'an insignificant nothing'.

On another occasion a government worker comments, 'if there were so many rapes where were the pregnancies?' Jenny's narration describes how she was 'nearly sick' in response, capable only of a silent scream, whilst her companion, Bonney Djuric OAM, had the presence of mind to retort: 'they knew our cycle'. Bonney's stark comment evokes the reality of the intrusive surveillance that supported institutionalised abuse in the setting the visitors now inhabit. The work thus brings to visibility the emotional valences of micro-interactions in social and institutional settings as colleagues and I have theorised elsewhere.⁷

There are many purposes—reparative, psychological and political—to this work, not all apparent in the film itself. In a recorded interview, Jenny describes its meaning to her in terms of 'being believed' and in enabling her son to understand her experience (McNally, 2017). The film itself ends with the Parragirls' call for FACS to be accountable. To date, we have been able to use its screening to broker dialogues between the women with the FACS leadership team and other political and community leaders. None of these goals is an end in itself; they express a principle behind the collaboration, which is to ask 'who needs to see and hear this?' (and more exactly, for the Parragirls, 'who do you need to see and hear this?'), and then to facilitate viewing and listening in mutually beneficial settings.

In 2017 the festival also launched a continuing project, *Awkward Conversations*, which provides a framework for 1:1 conversations in supportive settings, the aim of which is to 'design away' barriers to communication.⁸ These conversations have also provided a catalyst for developing new projects. 'The S-word', which began as a hosted conversation about suicide has led to a further project in the 2019 festival, using virtual reality to cultivate future thinking (bringing to bear insights from neuroscience and psychology as well as lived experience and the arts). Similarly but to different ends, Debra Keenahan, an artist with achondroplasia dwarfism who staged a conversation in which participants walked with her through *Circular Quay*⁹ has developed a Virtual Reality (VR) experience called *Being Debra*. The latter goes a step further than the conversation which set out to share the experience of public hostility by offering users a first-person perspective.

Brief comment should be made regarding the centrality of VR as a tool in fEELs/The Big Anxiety's research program. VR is deployed in research exploring the nature of first-person experience as embodied—physical, cognitive, emotional and neuropsychological—but also situated in social interactions. As with the Parragirls film, this opens up a dynamic exploration of the impact of interactions, and in turn of wider cultural practices of empathy and its limits. Debra's experience of public engagement is of a hostile environment. Passers-by routinely stare at her, abuse her, patronise her. She is intrusively photographed and sometimes physically intimidated by young men. More 'polite' or inhibited responses are simply avoidant or embarrassed. Her experience is of a general lack of empathy, fuelled by a discomfort with visible difference.

The weight of evidence from psychology and neuroscience suggests that empathy is generally directed to people we like (in-groups) and withheld from people we regard as unlike ourselves (out-groups).¹⁰ As such, empathy is highly selective and in the absence of critical reflection may serve to reinforce social boundaries and thereby stigma and discrimination. Perspective sharing, which can be powerfully enabled through VR, is a necessary if not sufficient condition of empathy. Hence VR is a useful tool in a wider inquiry into the mechanisms by which empathy may be cultivated, extended and maintained—an inquiry which begins with identifying the limits of our capacity for empathy, and the points at which it is enacted and withheld in social settings. Crucially, then, our research does not simply envisage empathy as a psychometrically measured trait but as a felt interaction, shaped by cultural and institutional practice.

This is vital territory not only because mental health needs specialised work in communications and engagement. At the same time, corporate culture is evolving an 'experience economy' in which empathy is increasingly commodified. Facebook rhetoric now equates empathy with its own mission of expanding choice and access to personalised shopping; and 'experience designers' now create and purvey 'experience' as total product. In this climate the popular notion of VR as an empathy machine is undoubtedly as dangerous as it is promising. But not to be ignored. The affective turn in cultural studies and humanities grounds critical inquiry in the dynamics of empathy; and it enables more skilful attunement to the emotional valency of expression and communication. As a project of practical aesthetics, this takes us beyond the study of representation. It is the basis for fostering the psychosocial supports we need to ensure cultural change.

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