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Issue 1

Problematising lived-experience

Stories, Identities and Knowledge

I have often struggled with the concept of lived-experience. Even before taking up a designated lived-experience role at The Australian National University, I had actively dis-identified as someone with a lived-experience, despite sharing several interests and commitments with the user/survivor movement.

My first point of contact with the notion of lived-experience was through my interest in literature and ethics; in particular, the ‘illness narrative’ – a relatively modern genre of autobiographical and biographical writing. Janet Frame’s, *An Angel at my Table* (1984), William Styron’s *Darkness Visible* (1989) and Jean-Dominique Bauby’s (1997) *The Diving Bell and the Butterfly* were just some of the works I read that had a profound impact on me. These and other powerful, evocative personal stories brought me into the emotional lives of people embroiled in complex and difficult situations, deepening my understanding of illness, madness, addiction, disability and dying.

The relationship between life, experience and narrative is complicated. Experience is a lived, messy and ongoing process, so just how do we separate it from the flow of human life and give it shape and meaning (Fox 2008; Lu & Horner 1998)? Stories are seen as one of the primary ways of imposing order and meaning upon the raw flow of human experience (Abbott 2009). Fashioned through processes of memory, reflection, interpretation and telling, the storying and re-storying of experience emerges not only because of our need to give shape and meaning to our lives, but because of our need to communicate our experiences to others.

Viewing experience as independent from the ways it is represented, however, leaves aside questions of how stories are influenced by history, language and culture. Despite a measure of narrative freedom, the expression of personal or private experiences is always through the prevailing cultural conventions of storytelling such as genre, plot, character and theme (Atkinson 2009). Indeed, the struggle by those with lived-experience to wrest control of their stories from the objectifying, pathologising and dehumanising language of medicine signalled a hard-fought shift toward transforming social and political writing about mental illness, madness, disability, suicide and addiction.

Given that personal stories are shaped by culture and language, they have the capacity to reproduce prevailing cultural norms and beliefs, as well as to transgress or subvert them. My previous work examined the conditions in which stories of lived-experience were produced in suicide prevention and the prevalence of certain story types, most notably those of recovery and resilience (Fitzpatrick 2016; 2020). Similarly, for those conducting qualitative research into people's experience of health and illness, the ethics and politics of representation are nested within important questions of truth, power, social reality and voice. Like quantitative research, qualitative research provides 'ways of seeing' that privilege and value certain kinds of evidence, reasoning and knowledge over others.

Stories also play an important role in identity formation – both the stories we tell ourselves and those that are told about us. Perhaps my biggest concern in taking up a designated lived-experience role was the sense of discomfort I felt in having to potentially disclose my personal experiences to others. This was less to do with any concerns over authenticity or legitimacy as described by Veronica Heney, but rather out of the fear that some singular identity category was about to be thrust upon me and the implications of this both personally and professionally (Heney & Polykett 2022). Fortunately, as my position allows, it is enough for me to identify as someone with a lived-experience without having to disclose my story or fit within some prescribed definition of what lived-experience entails.

Writing from the first-person, Heney notes that this claim to privacy is not equally shared by all (Heney & Polykett 2022). Like Heney, my position within the academic space affords me certain privileges, allowing me to position myself as a scholar rather than as a service user or survivor. However, as Heney acknowledges, there are those whose race, class, disability, or particular experience of illness and/or distress restricts their access to these spaces and the protections they provide.

Jijian Voronka (2016) raises a set of related questions about identity, difference, social position and organisational culture that further unsettle established uses of the term ‘lived-experience’ and the practices of knowledge production authorised under its name. First, how does positioning ourselves under the collective banner of ‘people with lived-experience’ work to erase important differences (for instance, those between individuals who identify as peers, service-users, carers, psychiatric survivors, or mad)? Second, how do individuals come to be recognised as qualified lived-experience experts able to gain access to and work within mental health or other professional spaces?

Individuals invariably use their lived-experience in different ways within different contexts. The conditions in which lived-experience knowledge is produced, therefore, are important for understanding the possibilities and limits of knowledge production (Voronka 2016). For Voronka, this is especially important where individuals with lived-experience are asked to represent others, or where those with lived-experience work collectively to produce knowledge outcomes.

Negotiating critical differences and the authority of lived-experience in these situations can be difficult. There are times where this can be creative and productive, but equally, it can also lead to conflict and complicity with existing systems of power.

In drawing attention to the ways that knowledge is produced under the "rubric of 'lived-experience'", Voronka (2016) invites us to consider the risks of conflating important conceptual and ideological differences, and the boundaries of occupying such an identity within mental health research and service systems.

Reflecting upon the concept of lived-experience calls for careful analysis of its underlying norms and values, the knowledge generated from it, and the subsequent social and material outcomes. Such reflection, I believe, is necessary to tackle important ethical and political challenges within lived-experience practice while advancing the field.

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Issue 2

The Institutionalisation of Lived-Experience

Taming Liberatory Possibilities?

In my first piece, I highlighted several issues with the way 'lived–experience' is used within mental health research and the practices of knowledge production authorised under its name. In this piece, I would like to extend this work by drawing a number of parallels between lived–experience research and recent research on peer work. In doing so I hope to provoke debate about the liberatory possibilities of critical scholarship, advocacy and support work in these fields, and processes of institutionalisation that frequently impinge upon them.

Like peer work, lived–experience involvement in research is a valuable and essential part of health and medical service system design and delivery. In addition to conducting research that is relevant to community and service–user needs, it can also improve the quality of research design by ensuring research outcomes and methods are informed by lived–experience perspectives (Slattery et al., 2020). This has resulted in opportunistic (and often uneven) forms of collaboration between non lived–experience researchers and those with lived–experience, with repeated claims of tokenism and co-option. However, opportunities have also emerged within university, community–based and governmental settings for those with lived–experience to establish and build careers in research (Kalathil & Jones, 2016).

Recent research on peer work has touched upon the uniqueness of the peer role and the freedom given workers to negotiate the boundaries of their practice to work in flexible non-traditional ways, including recognising the sometimes distressing and disempowering effects of standardised treatment regimens and outcomes (Berry et al., 2011). This research has shown that the practice of peer work is shaped not only by lived–experience, but by vocational education and training (Kessing, 2022). In this view, peer knowledge is seen to constitute a spectrum of knowledge combining expert knowledge with personalised and intuitive lay knowledge (Kessing, 2022).

In much the same way, lived–experience researchers have begun to carve out spaces in which to engage with and transform the languages, concepts, practices and systems of mental health research and care (Menzies et al., 2013). Recognising the disempowering and dehumanising effects of much conventional mental health research, lived–experience researchers draw upon their own experiences, as well as diverse fields of inquiry, knowledge and methodologies to provide a more inclusive view of service-users' and survivors' experiences and aspirations.

Despite, positioning themselves in various ways in relationship to mental health professionals and services, lived–experience researchers share a number of values and perspectives. These include inclusivity, collectivity, respect for the experience and viewpoints of others, and anti-oppressive, social justice principles. Research on peer work suggests these values, and indeed the very authenticity of peer work may be compromised by forms of institutionalisation, especially where the peer role is diluted to conform with existing care mandates or subject to processes of socialisation by dominant professional cultures (Cleary et al., 2018; Kuek et al., 2021). The expectation for peer workers to challenge and transform mental health practice, therefore, needs to be balanced against the view that they can do so often within the bounds of non–peer professional practice only (Berry et al., 2011).

The same point of tension exists between the knowledge produced by lived–experience researchers and so-called ‘scientific knowledge’. Evidence hierarchies that privilege specific methods or forms of evidence over others, together with the veneer of scientific objectivity that characterises much mental health research continue to marginalise lived–experience research (Carter et al., 2011). Even within co-created research, non–lived experience researchers may seek to maintain the power, credibility and primacy of their knowledge in relation to those with lived–experience through methodologies that eliminate context, culture and subjectivity from consideration (Fitzpatrick et al., 2023).

Building upon the grassroots work of the service-user and survivor movement, a considerable body of lived–experience research continues to focus on challenging dominant assumptions about mental illness, as well as sanist norms and practices in health services and society. Lived–experience research, then, is very much concerned with addressing the struggles confronting individuals and communities in ways that are ethically and socio-politically engaged. Central to this task is the critical appraisal of psychiatric power, knowledge, diagnoses, treatments and related systems of health care (Bracken & Thomas, 2005).

Such activist impulses do not always fit easily within the parameters of the modern research university. Mobilising against powerful institutions and interests is not easy. Moreover, the vulnerability of lived–experience knowledge to processes of assimilation and neutralisation mean that institutions may be motivated more by preserving their own power than by redressing existing power and knowledge asymmetries (Kalathil & Jones, 2016; Voronka, 2019). Such ongoing challenges are an inevitable part of working within established systems. This is particularly evident when this involves the design and implementation of services within the mental health service system, or when research is produced within the competitive, increasingly commercialised university sector where government and industry funding play a key role in shaping research priorities.

A key point of concern, then, is whether it is possible to work within these institutions without undermining the fundamental values that underpin the service user and survivor movement (Penney & Prescott, 2016). Darby Penney and Laura Prescott (2016) ask whether it is possible to undertake peer work within the mental health system that embodies an ethic of reciprocity without becoming hierarchical? Similarly, as lived–experience researchers we must ask ourselves to what extent can we conduct scholarly work that is curiosity-driven, critical, self–directed and sustainable, rather than being shaped purely by institutional and political–economic interests (Lave, 2012).

"While the spirit of revolution", to quote Robert Menzies and others (2013, p. 21), "is an intrinsic element of every collective struggle" so too are the immediate challenges. With many peer workers and lived–experience researchers committed to working within existing institutions, spaces that offer autonomy and the opportunity to engage in critical research, teaching and learning need to be fostered and encouraged. Examining processes of institutionalisation across the contexts of peer work and lived–experience research is also vital if the liberatory possibilities of these practices are to be fully realised.

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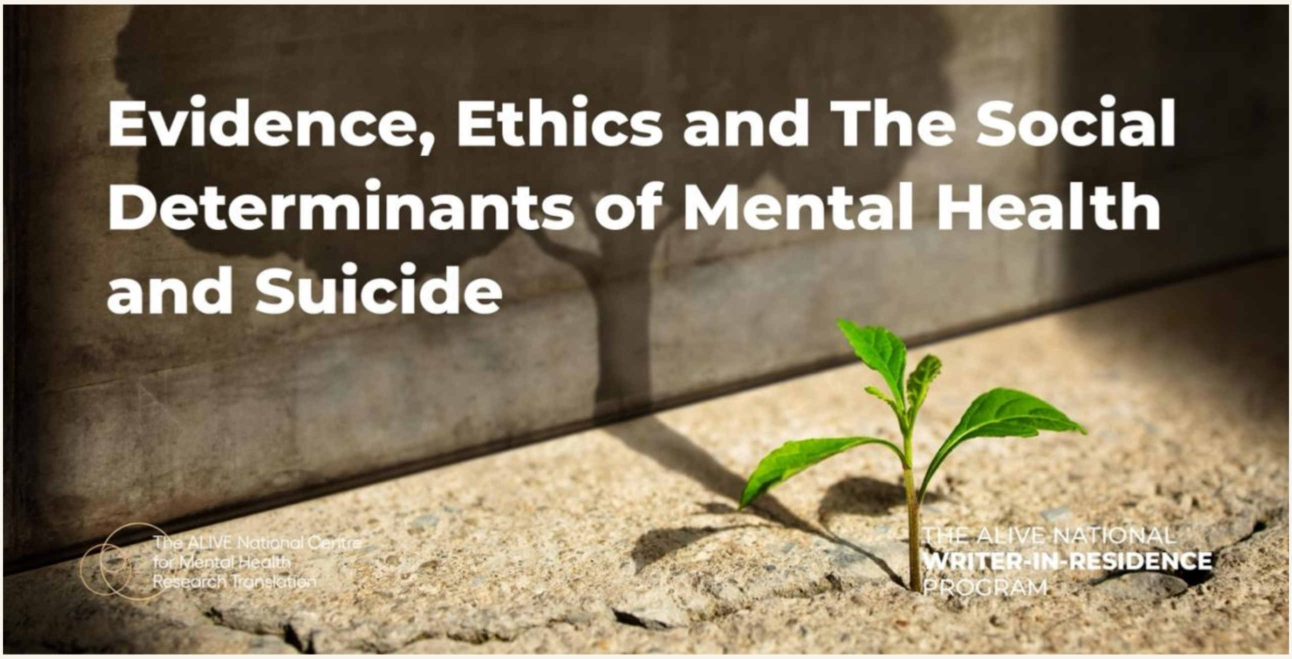
Issue 3

Evidence, ethics and the social determinants of mental health and suicide



The recent round of funding opportunities for research on the social determinants of mental health is long–overdue. Whether they signal a change in the way mental health and suicide are responded to in national and state policy agendas, however, remains unclear. Public health researchers and organisations have long argued for policy to address the social determinants of health to eliminate health inequalities. However, this is proving a considerable and ongoing challenge.

The social determinants of health provide a conceptual framework for understanding the political, socioeconomic and cultural factors that impact patterns of health and disease at a population level (Collins et al., 2007). The term health inequalities is closely linked to the social determinants of health and refers to the systematic differences in health status between and within social groups (Exworthy et al., 2003). The causes of health inequalities are complex and involve working and living conditions, health-related behaviours and accessibility to health care (Schmidt et al., 2010). However, different ways of framing these issues convey different ways of understanding the problem. Inequalities may be seen to be the result of the behaviours of certain groups. Alternatively, they may be seen to result from factors beyond people's immediate control such as material–structural factors (eg, income, working conditions, housing and unemployment) (Baker et al., 2018; Oliver & Nutbeam, 2003).

The mental health and suicide prevention communities are certainly engaged with addressing the social determinants of health. In most cases, however, this involves a focus on specific disadvantaged groups or communities with interventions typically taking the form of health promotion or education programs aimed at improving community awareness of mental health risks, symptoms, prevention and treatment.

To many public health experts, the sources of health inequalities are primarily material–structural in origin (Raphael, 2015). Research shows that household income, unemployment, low educational attainment, social isolation, along with gender and Indigeneity are associated with poor mental health outcomes (Allen et al., 2014; Silva et al., 2016). There is also a strong association between socioeconomic status and suicide (AIHW, 2023). In this view, health *inequalities* are *inequities* driven by the unfair distribution of power, money, resources and opportunities and require some form of political intervention to reduce them (Oliver & Nutbeam, 2003). This raises difficult ethical questions and inevitable clashes between competing priorities and values.

Although important, increased funding for research on the effects of the social determinants on mental health and suicide suggests that research evidence alone dictates policy decisions. However, theoretical perspectives of policy making as a rational, linear process in which evidence is transferred directly into policy has been shown to be out of step with how policy making occurs in practice (Baum et al., 2013; Crammond & Carey, 2016). While policy is supported by evidence, it is also driven by the values and interests of key actors (Baum et al., 2013; Exworthy, 2008).

A 'crowded' health policy agenda and the constant pressure on acute care services mean that policy action on the social determinants of health is invariably pushed to the margins (Baum et al., 2013; Hauck & Smith, 2015). The role of the medical profession in capturing public, media and government attention and influencing the policy agenda toward clinical interventions should also not be overlooked (Baker et al., 2018). The politicised use of research evidence by prominent researcher/policy advocates has been shown to be a factor in recent Australian mental health reform (Whiteford et al., 2016).

The feasibility of policy solutions has also been questioned. The complex, multifaceted pathways linking the social determinants with adverse mental health and suicide outcomes are misaligned with the preferences of government for clearly defined, conceptually simple policy solutions (Baker et al., 2018). Policy action on the social determinants of health often fall outside of the health sector. As such, they require coordinated responses across the whole of government to develop and implement health promoting policies in non–health sectors such as education, housing and welfare (Baker et al., 2018; Crammond & Carey, 2016).

This raises challenging questions about the role and responsibilities of government. Ideology, which can be defined as an overarching paradigm of principles, beliefs and assumptions that provides bureaucrats, policy experts and politicians with ways to frame solutions and shape public opinion is frequently cited as a barrier to political action on the social determinants of health (Baker et al., 2018; Béland, 2005). For those who believe the responsibilities of government are to provide services to the community, manage public spending, encourage economic growth, and support innovation and private industry there is likely to be strong resistance to redistributive policies targeting health inequities.

To this end, some have argued that strategies that can be implemented within existing policy objectives may have a better chance of succeeding than those that directly challenge them (Schmidt et al., 2010). Katherine Smith’s (2015) work is insightful here. Interviewing researchers, public servants and politicians who had undertaken work on health inequalities, she found that interpretations of current political contexts were communicated by public servants to researchers in ways that consciously shaped their decisions about which research projects to pursue or how best to present results in order to be viewed as 'credible' by policy audiences, most notably ministers and their advisors.

Smith's (2015) work shows how complex networks of actors and organisations play an important role in perpetuating (or resisting) dominant political and economic ideas. Rather than viewing 'government', 'political context' or 'political ideology' as an overarching social force that people are relatively powerless to challenge, she asks us to consider the ways that we, as researchers, advocates, organisations and media may be inculcated into certain ways of thinking and working that perpetuate the status quo; ways of thinking and working that need to be challenged if health inequalities are to be reduced.

Because health inequity is an ethical concept that describes empirical phenomena in moral terms, researchers would do well to connect policy issues with ethical and political analysis (Embrett & Randall, 2014; Gamble & Stone, 2006). To date, there seems to be a general neglect of policy analysis in mental health and suicide prevention fields that considers the ethical and political bases for decisions relating to, for example, the prioritisation of problems, the weighing of values (such as fairness and efficiency), and the allocation of resources, not to mention the impacts of current government policies on mental health in areas such as welfare, housing and immigration. To generate policy change that addresses the social determinants of health inequalities there is a clear need to make these decisions explicit and subject to critical scrutiny. Evidence alone is not enough.

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Issue 4

Un/doing Suicide Prevention

Last year I had the pleasure of reviewing Alexandre Baril's groundbreaking *Undoing Suicidism: A Trans, Queer, Crip Approach to Rethinking (Assisted) Suicide* (2023). Building and expanding upon previous work, most notably his conceptualisation of 'suicidism' (Baril, 2020), Baril draws upon queer, trans, crip and Mad theoretical frameworks as well as his own personal experience of suicidality to make a compelling case for rethinking the ways we conceive of and respond to suicide.

Suicidism, according to Baril, describes the oppressive system that discriminates against often already marginalised individuals and communities experiencing suicidality. At the centre of this system is a 'preventionist logic' embedded within various institutional settings, cognitive frames, laws, interventions and discourses that purport to save lives and 'fix' suicidal people, yet which often result in harms to individuals through practices that silence, pathologise, exclude, label incompetent, detain and forcibly treat.

Closely bound to this preventionist logic is what Baril refers to as an 'injunction to live' that both renders an individual's desire for death as abnormal and unintelligible, and imposes on them a normative obligation to themselves and to others to manage, preserve and optimise their mental health and wellbeing. Or alternatively, as Baril claims, leads those experiencing suicidal thoughts to shut up, remain silent or respond with well–rehearsed platitudes about their personal safety to avoid any negative repercussions.

Through diverse testimonials Baril describes how many people feel unsafe discussing their suicidal thoughts despite public health campaigns actively encouraging this. For Baril, the disclosure of suicidal thoughts promoted through these kinds of campaigns is one thing, yet any reflection on whether suicide is a valid option, he argues, is almost always discouraged. Suicidism, the system, quells any such discussion. Yet, for many, suicidality is a complex and meaningful phenomenon that demands exploration.

Baril's work struck a chord with me, resonating with my own developing ideas about suicide as an understandable response to suffering (Fitzpatrick, 2020), yet conveying the nuanced, complex and layered terrain in which such understandings sit. There were also certain parallels between the lack of support for those experiencing suicidality as described by Baril, and research I recently carried out on suicide in older adults (Fitzpatrick et al., 2021). In this research, the desire to die was responded to in one of two predominant ways. First, with rules-based risk management strategies that prevented practitioners from engaging relationally with those in distress and the existential despair most of them faced. Second, through practices of involuntary detention and treatment that were readily deployed to contain and prevent threats of self-harm, even when this violated an individual's body, human rights and dignity. This resulted in many people dying alone and in silence.

Baril's work also resonates strongly with the Alternatives to Suicide (ALT2SU) Project; an approach that creates spaces for mutual connection and meaning–making around suicidal distress, thoughts and experiences. This approach holds people 'responsible to – and not for or over others.' That is to say, while one cannot be responsible for another person's choices or actions, one has a responsibility to be present with one another and to validate, explore and speak candidly about personal experiences.

For Baril, openly discussing suicidality and the desire to die is not antithetical to forms of accountability and support, although these should be based on processes of accompaniment rather than prevention. To this end he advances a ‘suicide–affirmative approach’ anchored in the values of anti–oppressive social movements, self–determination and harm reduction that stands in opposition to dominant approaches based on risk aversion and moral fears around suicide and its potential ‘contagion’. Pre-empting arguments that normalising suicide has the potential to influence already vulnerable individuals, Baril contends that more open discussion of suicide within a suicide–affirmative approach may actually result in more people experiencing suicidality seeking support by reducing stigmatisation.

The suicide–affirmative approach can be operationalised at different levels (eg, law, public policies, health care and social services). When applied to health care it involves an emphasis on peer support, respect for autonomy and self–determination, a nonjudgmental attitude, the refusal to use nonconsensual and coercive interventions, and a set of compassionate and pragmatic approaches that seek to reduce harms stemming from high–risk behaviours.

Baril is at pains to point out that the arguments presented in *Undoing Suicidism* are not intended to encourage suicide. The approach aims to reduce suicidality among specific marginalised groups overrepresented in statistics on attempted suicide and suicide including queer, trans, disabled and Mad people. Full recognition of suicidal people, however, means that a suicide–affirmative approach extends to a positive right to die for suicidal people. This includes support for assisted suicide.

Such a position is contentious, and Baril rightly anticipates criticism of his dual life–affirming and death–affirming stance, as well as the significant hurdles that need to be overcome if social, political and legal change is to be realised. However, as Baril suggests, all transformation must start somewhere. As such, he sees his work as a form of micro–resistance aimed at making visible the voices of those who are suicidal in the hope that a ‘suicidal epistemic community’ will emerge to fill the gaps in our understanding and better meet the needs of those who repeatedly struggle with thoughts of life and death.

Undoing Suicidism is a deeply considered and courageous work that offers an unapologetically moral stance against discrimination and exclusion as the basis for reimagining suicide, social action and caregiving. It asks no more (and no less) of us than to let go of our attachments to certain ideas, ways of knowing and beliefs. This is certainly something the field of suicide prevention needs to do more.

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Issue 5

Space, Place and Experiences of Distress

For much of the previous decade the focus of suicide prevention has been on improving access to mental health services. Public health campaigns and education programs aimed at improving knowledge of the signs of distress, together with service delivery approaches that provide different intensities and modalities of care have been regular features of policy and practice. This approach, however, has often overlooked the fact that many people choose not to access health services for suicidal distress due to dissatisfaction with mainstream services, ineffective treatment, or previous contact with uncaring practitioners (Pitman & Osborn, 2011).

A key success of lived–experience involvement in the sector has been to draw attention to these concerns and to emphasise that services are not inherently beneficial in and of themselves, but have the potential to cause harm (Pilgrim & Rogers, 2005). As touched upon in my previous piece, under–resourced public hospitals and community mental health services, impersonal risk assessment procedures, no–suicide contracts, the pathologisation of suicidal thoughts, and the threat of involuntary detention can contribute to the creation of unsafe environments for those experiencing suicidal thoughts or distress.

The need for safe spaces for those in distress or crisis is in many ways self-evident. Many of these people have experienced trauma, may live or work in unsafe environments, or be involved in unsafe relationships or practices (Everett, 2009). The establishment of a National Safe Spaces Network seeks to address the above concerns, providing peer–led, non–clinical alternatives to care in a range of settings. Still in their infancy, not much is known about safe spaces. To address this research gap, the Co-Creating Safe Spaces project is currently underway with the aim of evaluating different safe space models across Australia.

Idealised and decontextualised notions of 'community' present in the term 'community care' has meant that little attention has been paid to specific sites of care (McGrath, 2012). The role of 'place' and 'space' in healing and recovery, however, is an integral part of how distress is responded to in society and has been well documented by geographers. Historical analyses illustrate the changing geographies of places and spaces of care for people with mental illness from the asylum, with its complex geographies of care, control and cure, through to contemporary psychiatric settings and the so–called post–asylum landscape that includes care in the community and nonmedical landscapes, such as natural and social environments (McGeachan & Philo, 2017).

Discussions of space and place are especially salient given the shift to community care and the importance of community participation and social inclusion in promoting recovery and wellbeing (Duff, 2012). The move from segregated institutional environments to normalised community settings, after all, has not resolved issues of stigmatisation, fear and exclusion for those experiencing distress, those deemed 'at–risk' of harm, or those labelled with a mental health diagnosis (McGrath & Reavey, 2015). Moreover, people who suffer mental health problems or experience distress often have very few safe spaces in the community and report frequent social isolation (Pinfold, 2000).

A key focus of research on place and mental health to date has been on the way people act, interact and move within spaces. This relational and dynamic understanding of space acknowledges the social, material and affective characteristics that shape experience (Duff, 2012). The social, according to Duff (2012), refers to the way spaces shape and mediate social interaction. The material aspects include those activities that specific spaces foster or make possible via their physical structure (eg, the built and natural environments), while the affective refers to the feelings generated by the physical and social experiences of space.

Laura McGrath's (2012) work shows that people negotiate their distress across multiple spaces such as the home, community, the workplace and services, and that this can result in 'concordant' and 'discordant' experiences. McGrath's work is insightful, taking us beyond conventional thinking about the medical or socio-political 'causes' of distress and its management to consider its dynamic nature and the influence of the spatial context in which it occurs.

Given the challenges of managing distress within and across a multiplicity of spaces, there are strong arguments for the creation of spaces that offers refuge, respite, and where expressions of distress are accepted and acceptable without an underlying agenda of treatment and recovery (Bryant et al., 2015; McGrath, 2012). This sentiment is captured perfectly by a lived–experience respondent in the recent National Safe Spaces Network Scoping Study: 'People don't just want treatment; they want a "safe space to fall, a safe space to fall apart"' (KPMG, 2020 p. 123).

These developments, among other things, provide a timely argument for rethinking concepts of safety and associated practices that drive many of our suicide prevention efforts, yet that manifest differently within and across different spaces, and often, with very different outcomes for those experiencing distress.

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Issue 6

Democratising expertise

Some reflections on the concept of suicide literacy

I recently had the pleasure of attending the conversation with Diana Rose and Michelle Banfield to discuss Diana's book Mad Knowledges and User Led Research (2022). I was particularly struck by Diana's comments about the unique position of mental illness in comparison to physical illness, and the ways professional knowledge is accommodated, contested and resisted. That is to say, while it is rare for expert descriptions of physical illness such as asthma, diabetes, cancer, heart failure and so forth to be actively contested and resisted, expert medical descriptions of mental health conditions frequently are.

While there are those who find the knowledge of psychiatry and related fields useful for understanding their symptoms and experiences, there are many whose experiences are at odds with dominant biomedical understandings. In the field of suicide research and prevention this discordance is arguably even greater still. A growing body of research from those with lived–experience of suicidality reports a level of divergence between their experiences and the language of medicine that negates rather than makes these experiences meaningful (see, for example, Webb, 2010). Despite the self–evident differences between biomedical accounts of suicide and lived–experience accounts, Diana's comment reminded me again of the brittle foundations on which 'expert' knowledge of suicide rests.

Of course, patterns of discrepancy are also common to understandings of some physical health conditions such as COVID–19, as well as other areas of scholarship such as human–caused climate change and evolution. These are frequently labelled as denialism. And while denial and avoidance of mental illness diagnoses also feature in the medical literature, one could argue that this does not so much represent an "organised attempt to undermine our collective ability to understand the world and change it for the better", something that Keith Kahn–Harris (2018) sees as a key feature of denialism, as much as it is the result of distinct schools of thought or paradigms. After all, conceptual models of mental health and suicide abound from neuroscience to Mad studies (Richter & Dixon, 2023).

It is for this reason that I have always found the concept of suicide literacy difficult to square with the basic tenets of lived–experience participation. Incorporating aspects of mental health literacy, suicide literacy refers to public knowledge about the causes of suicide, risk factors, signs, treatment and prevention. Not only does it presume a gap in knowledge about suicide that acts as a barrier to people seeking and receiving treatment, it views the knowledge or attitudes of certain individuals and groups as less worthy than expert knowledge. Published studies repeatedly refer to individuals' 'poor recognition of warning signs', 'negative beliefs about medication' and 'lack of compliance with treatment' (Fitzpatrick, 2020). Framed in this way, certain individual and public beliefs and attitudes are seen to contrast sharply with professional knowledge, signalling a divide between experiential or anecdotal knowledge and expert or 'scientific' knowledge.

Rarely in the suicide literacy literature is the construct of expert knowledge interrogated in any critical way, despite a significant body of research showing that improvements to health professionals' knowledge, attitudes, communication and clinical skills are needed when working with people in suicidal distress (Boukouvalas et al., 2020). Furthermore, the literature consistently overlooks the evidence which shows that personal experiences of suicidality can diverge significantly from expert discourses yet still provide opportunities for self and social empowerment.

Equally problematic is the narrow definition of literacy put forward in the literature that views it primarily as the transfer of packaged information by experts to a passive target audience (Chinn, 2011). Evaluation outcomes that typically consist of short–term measures such as gains in suicide prevention skills and knowledge suggest that these outcomes can be achieved in relatively short periods of time; a curious position to adopt given the acknowledged complexity of suicide (Ranahan et al., 2017).

Didactic approaches to suicide prevention awareness and education are liable to several additional objections. First, knowledge that is reduced to the narrow practice of identifying and assessing suicidal risk denies the cultural experiences of those individuals and groups who are the subjects of these programs. In viewing suicide as something that is managed within discrete, standalone conversations between individuals, it is separated from important relational, sociocultural and political issues that are often intrinsic to understanding a person's desire for death (Ranahan et al., 2017). Second, they adopt a hierarchical and elite approach to pedagogy that denies the value of what learners know, especially in relation to local needs, histories, culture, and experiences (Giroux, 2005; Licona & Chavez, 2015). Understanding suicide in context, however, is important and provides communities with new ways to learn together and respond appropriately (Ranahan et al., 2017).

Drawing on community development and empowerment perspectives such as those developed by Paulo Freire (2005), recent critical literacy work in suicide prevention education has redirected attention toward shared knowledges and the relational processes of co–creating those knowledges (Licona & Russell, 2013). Such approaches require a different pedagogical basis than those of conventional suicide prevention education programs; one that recognises learners as knowledgeable subjects, engages them in critical dialogue to understand issues, and encourages them to participate in decision making that impacts on their lives and communities (Sykes et al., 2013). In this way, skills that enable people to identify problems, reform systems and services, and exert control over environmental and socioeconomic factors influencing suicide become equally important objectives of suicide prevention education (Nutbeam, 2000).

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Issue 7

Utopianism, anarchism and ‘community’ mental health

In this, my final extended piece for the ALIVE Writer-in-Residence program, I explore the notion of community-based mental health from a utopian and anarchist perspective. Utopianism is a label that is applied to a variety of ways of imagining, describing or conceiving of a better society (Sargent, 2024). Anarchism, from a contemporary perspective at least, is less about the abolition of the state than about “exposing, delegitimising and dismantling mechanisms of rule while winning ever-larger spaces of autonomy from it” (Graeber, 2002). Utopia and anarchy are not wholly incompatible ideas, but only if the vision of a better life is provisional, partial and open to criticism and adaption (Kinna, 2009; Scott-Samuel & Smith, 2015).

A utopian vision of a society that cares for and supports those experiencing madness, distress and/or mental illness, addresses the contexts in which they arise, and upholds the legal rights of citizens is a common refrain in policy. What is missing from these perspectives, however, is a discussion of the strategies and practices needed to effect such change.

Of course the linking of utopian thought with mental health care requires some caution, and deservedly so. Commonly viewed as the active promotion of an idealised vision of a better society, utopianism is often regarded as fanciful or malevolent. Its universal blueprint of perfection derided as either unrealistic or achievable by repression and violence only (Levitas, 2000; 2013). In contemporary popular culture, a dystopian shadow lurks wherever utopian thoughts are expressed.

The utopian hopes which greeted the establishment of the asylum and the emergence of moral treatment in the eighteenth century is a case in point. Widely perceived to be the symbol of a humane and progressive society, some one hundred and fifty years later this very institution and its practices were considered a major obstacle to therapeutic success (Novella, 2008).

Heralding what some perceived to be a ‘new psychiatric paradigm’, the policy of deinstitutionalisation and the community-based model of care that replaced it, have, with few exceptions, failed to live up to expectations (Mechanic & Rochefort, 1990; Novella, 2008). Reflecting upon these issues in light of contemporary utopian and anarchist thinking, this piece will provide a brief account of community-based mental health care in the context of deinstitutionalisation before sketching some possible, alternative futures.

Anarchism and approaches to social change

One of the major misconceptions about anarchism is that it conceives of social transformation as the result of “cathartic revolution” (Ferrarotti, 1995, p. 260), and that “the reconstitution of society can only begin after the complete overthrow of existing social arrangements” (Honeywell, 2007, p.242). As Honeywell (2007) argues, this implies a dramatic and unfeasible rupture or change in existing institutions and behaviour as opposed to a focus on the here and now.

In contrast, the work of 20th-century anarchist writers such as Paul Goodman and Colin Ward emphasise the radical potential of immediate, pragmatic and piecemeal approaches to social change that are located in the conditions of the present

(Honeywell, 2007). From this perspective, the focus is very much on process, activity and movement rather than reaching some preconceived destination (Kinna, 2009).

The interrelationship between means and ends is an important feature of this approach, with the ends "fundamentally shaped by the means it employs" (Leach, 2013, p.1). This approach is closely tied to what is referred to as a prefigurative politics in which the strategies and practices employed by a particular movement shape or 'prefigure' the kind of outcomes envisaged (Fians, 2022; Leach, 2013).

Put differently, prefigurative practices typically attempt to anticipate those changes that are necessary to create the social relations, structures and systems that require transformation. For example, to build a more responsive, equitable, collaborative, holistic and inclusive community mental health service one has to employ responsive, equitable, collaborative, holistic and inclusive methods. Pragmatic and piecemeal actions such as these, typically found in effective co-design, do not necessarily herald a revolution, but this is precisely the point (Fians, 2022). What is required are a multitude of small activities that bring about gradual improvements in the world of everyday needs rather than wholesale top-down change (Honeywell, 2007).

While the practices employed vary based on the ideals of particular movements, they typically have in common decentralised, participatory and directly democratic forms of organisation (Leach, 2013). Decision-making processes are not the province of a handful of technocrats, but are instead situated in the activities of individuals and groups who seek to disrupt the self-perpetuating momentum of existing authoritarian and bureaucratic institutions (Honeywell, 2007; Scott-Samuel & Smith, 2015).

Deinstitutionalisation and community care

Deinstitutionalisation refers to a series of reforms that sought to redirect mental health care away from the institutional regimes of the asylum to community care settings. Whether this signalled a radical break from the past or was just one more cycle of reform among others is a point of conjecture among researchers (Novella, 2010). Growing patient populations, increased fiscal pressures on the state, the introduction of antipsychotic medications and a growing civil rights movement all contributed to the milieu in which the process of deinstitutionalisation developed (Mechanic & Rochefort, 1990).

The shift to community care, therefore, can be seen to include both a socially progressive element that was responsive to humanitarian concerns about the harmful consequences of the asylum, as well as a shift in rationalities to incorporate the functions traditionally associated with them into a coherent system (Rose, 1996). Regardless of these changes, public hospitals remain the foremost provider of mental health in-patient stays, although the range of preventive and curative activities previously associated with them are now dispersed among different levels of government and non-government organisations (Mechanic & Rochefort, 1990).

For many, however, community care was supposed to be more than the simple relocation of service provision from the hospital to the community. Instead, it signalled an attempt to dismantle the institutional barriers that prevent the full participation of people with mental health conditions in all aspects of life (Ben-Moshe, 2011). The task of bridging these gaps outside of the public hospital is a formidable one. In addition to medical care, those with severe and persistent conditions require secure and affordable housing, employment opportunities, help obtaining economic assistance, social support and activities (Mechanic & Rochefort, 1990).

Shortfalls in achieving these objectives, together with paternalistic relations between staff and service-users, the use of compulsory treatment orders, persistent social stigma and exclusion, as well as hierarchies of knowledge and power inscribed in research, policy and practice have led some authors to contend that the logic of institutionalisation is not limited to bricks and mortar institutions, but that it persists in the practices of community-based care (Ben-Moshe, 2011; Chow & Priebe, 2013). That is to say, institutionalised care is defined by its practices and not by its geographical location.

Pragmatic and piecemeal possibilities

Critiques of deinstitutionalisation, including claims that it has led to an increase in homelessness and to prisons becoming the new asylums, have resulted in growing calls by some psychiatrists for a return to institutionalisation as a way of providing accessible long-term care options for those with severe and persistent mental health conditions (Sisti et al., 2015). However, such arguments overlook government policies that have led to both growing prison populations and to a lack of affordable housing, not to mention giving the impression that institutionalisation is a solution for tackling these entrenched social problems (Ben-Moshe, 2020).

There is growing recognition that persons who experience madness, distress and/or mental illness must be protected from discrimination and mistreatment. Long-term hospitalisation has been shown to have little to no clinical benefit over care in the community, and may have a negative impact on existing symptoms, quality of life and lead to increased dependency on services (Chow & Priebe, 2013). Similarly, the harms associated with emergency departments for those experiencing distress or suicidal crises, as well as their families and informal carers, are well-documented in the research literature (Fitzpatrick et al., 2023).

The development and implementation of safe space models provide an alternative to acute care. Although initially designed to target those experiencing suicidal crisis, anecdotal evidence suggests an unmet community need for alternative non-clinical services (open door, peer-led and no restraint) for those experiencing a range of mental health and social issues. Although different safe space models exist, the emphasis on ongoing co-design with people with lived-experience seeks to ensure that these services meet service-user needs for compassionate, non-judgmental and person-centred care (KPMG, 2020).

Enhancing community-living, including the meaningful involvement of those with mental health conditions in the community, should be a keystone of community models (Ben-Moshe, 2011). It is therefore worth exploring the option of broadening the remit of safe space models to provide 24 hour support, as well as to serve as community access points for those seeking care and support similar to those found within the Trieste model of community mental health. In this model, community centres act as hubs for care evaluation, coordination, as well as social and therapeutic activities. Such a model also has the potential to inform development of a residential crisis service for those in need.

Alternative models of community care should extend beyond the provinces of medicine to include other professional and non-professional forms of expertise that are required to ameliorate distress and support community living, such as in areas of employment, housing and finance (Rose & Rose, 2023). Bringing about these changes is a long-term incremental process and requires drawing on community strengths, resources and the development of innovative service models.

As I have argued previously, participatory and democratic approaches to mental health literacy programs that utilise diverse local perspectives and cover topics such as medicalisation, how psychiatric drugs work, and the social and political determinants of mental health are needed to increase awareness of important issues, and to improve individual and community capacity to reform services and systems (Fitzpatrick, 2020).

As the Trieste model illustrates, the closure of institutions is only the first step and needs to be accompanied by a subsequent opening of society (Frances, 2021). This requires cultural change which does not happen without some organisation, persuasion and occasional turmoil (Colucci as cited in Frances, 2015). Given the myriad conflicting concepts and struggles over knowledge in the field of mental health, literacy is important to this endeavour as it provides an opportunity to examine political and ideological interests that shape cultural understandings (Freire & Macedo, 1987).

Concluding thoughts

Mental health policy in Australia is replete with rhetorical assurances of governments' commitment to improving the lives of those experiencing both common and severe mental health conditions. In practice, however, dispersed responsibility for managing and resourcing the mental health system across different tiers of government and nongovernmental organisations has transformed the sector, resulting in changing relationships between nongovernment organisations and the state. This, in turn, has led to increasing competition, regulation, service heterogeneity and the growing importance of commercial and market interests (Macdonald et al., 2018).

The marketisation of services has not come without its own fair share of ‘utopian’ thinking – from the promises of psychiatric molecular genetics through to information technology and the psychopharmaceutical revolution (Sadler, 2011). Yet evidence suggests that these approaches are unlikely to improve health and social outcomes for the majority of people experiencing mental health conditions. This is because community mental health care involves more than just the provision of psychiatric care. Reflecting on the current model and asking whether ‘another psychiatry’ is possible, Diana Rose and Nikolas Rose (2023) pose the following question:

> *[I]f structural violence, intergenerational trauma, social suffering, exclusion and the voice of the patient collectively conceived were recognised as foundational to the experience of both common and severe mental distress, would the medical discipline of psychiatry still be allotted the key role in understanding and treating mental disorders (Rose & Rose 2023, p. 52)*

Concern with the social, cultural and political issues that impact mental health such as those outlined above leads us back to discussions of community, and in particular, citizenship, with action needed to improve rights, social participation and access to resources (eg, nonclinical services, housing, employment and income) via a range of community interventions (Ponce & Rowe, 2018).

In helping to convey the sense that things are perhaps not as they should be, utopianism and anarchism endorse an idea of social change as rooted in the present and involving a multitude of small activities (Honeywell, 2007). Rather than seeking to determine a roadmap for the future, the purpose of this piece has been to imagine what might be possible and to open this up for discussion, while at the same time attempting to rethink the ways that a community-based mental health system could be created through means that are essentially democratic, non-hierarchical and inclusionary.

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