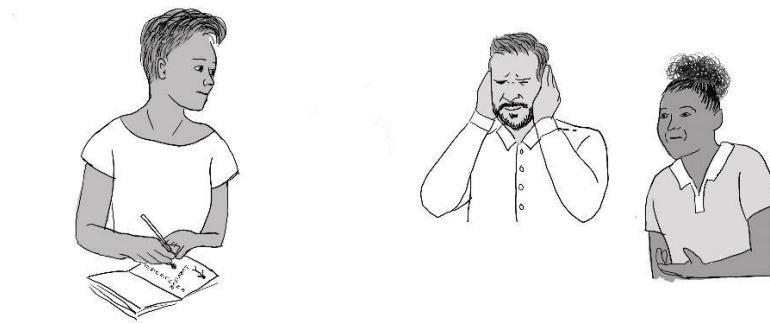


Zine and Heard?: mental health survivors, zines and epistemic justice

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A thesis submitted in partial fulfilment for the requirements for the degree of Doctor of Philosophy at the University of Lancashire

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Abstract

Survivors of the mental health system are marginalised in a myriad of ways in relation to knowledge production. This has increasingly been understood in terms of theories of epistemic injustice. Zines are often used to share marginalised peoples' knowledge, and the medium of zines and the zine community may have various qualities that might benefit survivors. However, there is limited research about survivors' use of zines, particular in relation to challenging epistemic injustice.

This thesis draws on interviews, zine-making workshops and a zine sharing session with survivors, as well as my own experiences of making and sharing zines, to provide an account of how and why survivors might use zines to reflect on and articulate experience, and how and why survivors might share experiences and understandings via zines. I used a zine-centred, survivor-friendly approach which draws on (critical) participatory action research, autoethnography, arts-based research and narrative research.

Themes discussed include: how the creative and crafty qualities of zines can help survivor reflection and articulation; survivors' use of the flexibility of zine structure to help sensemaking; and readers' responses to unusual structures and visual and sculptural elements in zines. I also discuss: how audience choice and context relates to social reflexivity, and what survivors felt able to articulate and share; the benefits that the culture of the zine community can afford survivors; and the way in which survivors engage in protective strategies and develop collective resources and agency via zines.

This thesis goes on to develop an understanding of how survivors' use of zines might help address epistemic injustice. It also demonstrates how theories of epistemic injustice and other relevant social concepts, such as Archer's (2000) account of agency, can aid our understanding of how and why survivors use zines.

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Dedication



This work is dedicated with much love to Maddy Smith 1971 -2023.

Introduction

This thesis explores how zines might enable survivors of the mental health (MH) system to reflect on, articulate and share their experiences and understandings with others. In this introduction, firstly, I define what I mean by zines and survivors of the MH system. I then outline why I decided to focus on survivors being able to reflect on and articulate and share their experiences and understandings with others. I then outline my own relationship with creative practices and why images are integral to this thesis. Finally, I outline the content and structure of the rest of the thesis.

Zines

Zines have been defined and described in a variety of ways. Duncombe (2017) defines them as “noncommercial, nonprofessional, small circulation magazines which their creators produce, publish, and distribute by themselves” (p.9). He further describes zines as being “somewhere between a personal letter and a magazine (Duncombe, 2017, p.13). Piepmeier (2008) describes zines as “self-produced”, “anti-corporate” and “anti-professional”, “quirky, individualized booklets filled with diatribes, reworkings of pop culture iconography, and all variety of personal and political narratives” (p.2). Fife (2019) describes them as resembling “a photocopied scrapbook rather than anything that we would otherwise consciously identify as a ‘publication’” (p.229). She further notes that “creators often appropriate, annotate and re-print copyrighted images, text and other copyrighted materials” and in this way illustrate “some of the central politics of zine culture – disrespect for institutional rules, professional techniques and the re-writing of majority and mainstream culture to reflect subcultural and often subversive values” (Fife, 2019, p229).

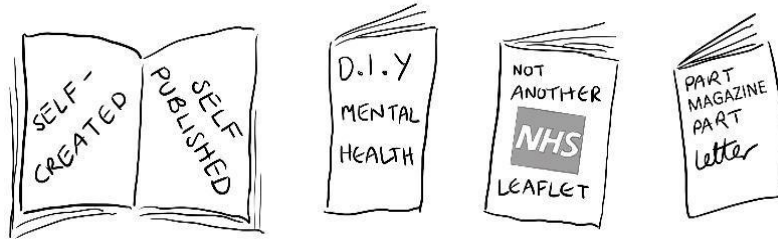


Image 0.1 Zines

In this study I simply define *zines* simply as self-created and self-published booklets. I do so because I see these as key features of zines and because I want to ensure my definition includes zines made by people who are not aware of the culture associated with zines (i.e. the DIY, non-commercial culture) and because I don't want to exclude zinesters who prefer to make their zines digitally.

Survivors of the mental health system

The BMA (2024) refer to the mental health care system as a system of health and social care services aimed at supporting people's mental health. They include in this NHS services and "voluntary and community sector" providers and they note the complicated nature of commissioning of mental health services in the UK (p.39). Meanwhile, Shidhaye (2023) describes mental health services as "any interventions, assessments, diagnosis, treatment, or counselling offered in private, public, inpatient, or outpatient settings for the maintenance or enhancement of mental health or the treatment of mental or behavioural disorders in individual and group contexts" (p.2). Similarly, when I refer to the *mental health system*, I mean the system of services that aim to support people with mental health needs. Although my focus is on people who have received statutory and clinical mental health services, I include voluntary sector services and services irrespective of support modality. I do so because in my 20+ years working in voluntary sector mental health services I found lines increasingly blurred between statutory and non-statutory and clinical and non-clinical services. My experience suggests that voluntary sector services are increasingly in receipt of state (NHS and council) funding, often because it is cheaper for the voluntary sector to provide services. Additionally, my experience

suggests that cuts to MH statutory services mean that many people who would have been in receipt of secondary statutory MH services in the past are now only able to access voluntary sector services and increasingly voluntary sector services mimic the language and practices used in statutory clinical services in their attempts to gain funding.¹ I use the term psy system to refer to psychiatric based services within the MH system and the term psy professionals to refer to psychiatrists, psychiatric nurses and psychologists².

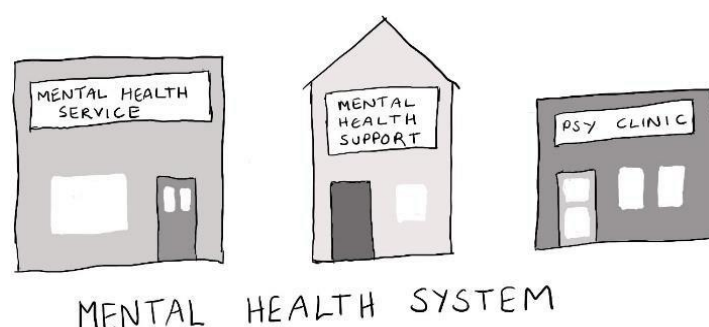


Image 0.2 Mental Health System

I use the term *survivors* to describe people who are, or have received services within the mental health system. I therefore refer to my participants as “survivors” although they might not all refer to themselves in that way.

Lindow (1999) notes that “There is no consensus about what people who receive mental health services like to be called: ‘service-users’, ‘survivors’, ‘recipients’, ‘patients’, ‘loonies’, ‘mad people’, ‘clients’, ‘consumers’ and (in Japan) psychiatrically disabled people’.” (p.154). As Lindow (1999) notes, “[t]he people who use the mental health system are not, of course, a homogenous group” (p.154). However, to be able to write about people who have received

¹ Cuts to welfare provision in the UK from 2010 have led to worsening mental health (Cummings 2018), especially amongst people on low incomes (Mattheys et al 2017). This included cuts to NHS mental health service and despite a recent increase in funding the British Medical Association have argued that in England “mental health services are not being resourced at a fast enough rate to respond to the level of demand” (BMA accessed 2025) and the editors of the Lancet argue that the recent increase in NHS funding isn’t enough to undo the previous 14 years of austerity and deep cuts to public services (The Lancet, 2024).

² In practice many psychiatric based services are staffed by a mix of psy and non psy professionals (e.g. occupational therapists, art/music/ drama therapists, social workers).

services in the mental health system, I need a single term. Whilst there are many possible terms I could have used, I use the term survivors of the mental health system instead of users, clients or consumers because many of my participants used this term in relation to themselves, because this term is widely used in the mental health service survivor movement and because I want to acknowledge that people might not choose to receive services and might not find them beneficial. I also use this term because it covers people who have in the past been in receipt of services but who are not currently receiving them.



Image 0.3 Survivors?

Survivor knowledge

In mental health systems, in my experience, survivor knowledge is often unvalued and not welcome or it is perceived to be restricted (e.g. we might be seen as knowing what colour we would prefer the walls of a clinic to be but we are not seen as knowledgeable about which treatments/service responses have improved, or reduced, our quality of life or how we might be best helped in the future). Additionally, my experience has been that survivors are expected to use the (diagnostic/therapeutic) language and concepts favoured by professionals and if we don't do this (or are critical of these) then we are perceived to be lacking in insight. Therefore, I decided to focus my thesis on how survivors could use zines to reflect on and articulate their experiences and understandings and share them with others. Like Creswell (2005), who describes survivors' testimony as knowledge and describes survivors as "experts by

“experience”” (p.1671), I see survivors’ accounts and understandings of our experiences as a form of knowledge.

I first got involved in MH system survivor activism around 25 years ago. I was motivated to get involved in part because of my own experience of spending nearly ten years in receipt of statutory mental health services, during which time I found professionals had little interest in my concerns, perspective, subjective experience or interpretations. Initially my involvement was as part of a group called *Women At the Margins* who were critiquing the diagnosis of Borderline Personality Disorder because we felt it didn’t enable survivors to make sense of experiences in the social, political and personal contexts in which they took place³.

I then spent over twenty years working in various roles in voluntary sector mental health services, including providing individual support and facilitating support groups, managing a service and doing lots of work around survivor involvement/voice. During this work I was regularly reminded of the difficulties survivors face when trying to reflect on and articulate experiences and/or when trying to share understandings and experiences. Sometimes this related to the resources survivors were expected to use to reflect on and articulate their experiences and sometimes it related to the barriers survivors faced when they tried to share their understandings and experiences.

Having resources with which we can effectively reflect on and articulate our experience is important for survivors to be able to make decisions about our lives. It is also important because it is the first step towards communicating our understandings and experiences and potentially affecting other people’s actions. For example, being able to reflect on and articulate why something caused us harm might enable us to make decisions to avoid the same harm in the future. Moreover, if we can also communicate this with others, they may avoid experiencing

³ One of the things we did, as *Women At the Margins*, was to create a special edition of *Asylum* magazine focusing on this issue (Shaw and Proctor, 2004).

the harm that we have experienced and/or they may be able to help *us* avoid the harm.

Survivor understandings and accounts of our experiences of being silenced or devalued, and our difficulties reflecting on and articulating experiences, are increasingly understood in relation to theories of epistemic injustice. Therefore, my theoretical framework is based on theories of epistemic injustice. I define epistemic injustice as unfairness related to what can be known. Discrepancies in access to knowledge, or to the means to articulate knowledge, can be unfair in the sense that they cause unnecessary harm and/or replicate or reinforce systems of disadvantage. I see knowledge as awareness and understanding, this can relate to internal or external experiences, and it can be gained (amongst other things) through experience and the application of theory or concepts.

My survivor-related creative practice

I have become increasingly interested in alternative ways that survivor knowledge might be articulated and shared, in particular the opportunities that cartoons, graphic media and zines might afford survivors in relation to our ability to make sense of our experiences and communicate them to others.

Alongside, and related to, my experiences as a service-user and a mental health professional I have a long standing and ongoing interest in illustration, graphic media and cartoons. I have regularly contributed illustrations and cartoons to *Asylum, the radical mental health magazine*; illustrated a book about parental self-injury (Shaw 2015), written a graphic memoir about my mental health related experiences (Walker, 2016) and worked with young survivors of abuse and exploitation to illustrate an educational resource they created, based on their experiences⁴.

For as long as I can remember, I have found it much easier and more effective to capture and communicate my ideas and experiences visually, to use images or a combination of images and words, rather than just using words alone. In addition to thinking in pictures during the process of this research I have found myself connecting ideas in my head through imagining creating a

zine, in much the same way that many people imagine having a conversation. Therefore, I often used images and pictures during the course of this research, and they came to be an important part of both my method and my way of communicating my ideas.

Although I ended up making many zines during this research, previously I had only made two creative objects that I'd describe as zines⁵: *Asylum at Highroyds* (appendix 1) and *Survivors Voices* (appendix 2). Both these zines were made in response to feeling silenced or unheard as a survivor of abuse and the MH system. *Asylum at Highroyds* is about an asylum where I had been an in-patient as a teenager. I made it because I wanted to record and share my experiences after I had been told that I couldn't take part in a project memorialising High Royds in the wake of its closure. *Survivors Voices* is about the importance of platforming the voices of survivors of sexual violence. I made it because I was frustrated at victim-blaming narratives in the media and the disparity between the number of reported crimes of sexual violence and the conviction rate. I experienced these zines as providing me with the opportunity to articulate and share ideas and experiences that I couldn't in other spaces.

Spandler (2020) used some of the cartoons I'd contributed to *Asylum magazine* as examples of how survivors can use single-panel cartoons as a way to contest psychiatric knowledge and practice. Spandler (2020) argued that psychiatric survivors' cartoons can "subvert epistemological privilege, identifying the mad person as the source of knowledge and understanding, thus decentering the role of mental health professionals" (p.127). They further wrote that "cartoons can achieve this without the use of inelegant academic language [which] is important in a discipline where critical ideas are often overly intellectualized and inaccessible." (ibid). In a similar vein, I found making zines enabled me as a person with lived experience to be the source of knowledge and my zines, like my cartoons, made use of simple accessible

⁴ This work was produced with the Reign Collective. See <https://www.reigncollective.org.uk/#>.

⁵ Other than my graphic memoir, which was initially created as a zine.

language and images. I understand it is for these reasons that Spandler developed the zine research project as a follow up to their research about single panel cartoons.

Spandler (2020) also argued that survivors' cartoons "can bypass rationality and reason to embrace alternative ways of viewing the world" (p.129). Moreover, cartoons can present critiques by appealing to "the collective experiential knowledge of the psychiatric survivor movement [and] well-rehearsed critiques of psychiatry. [and] to make their point they can draw on emotion, humor, and even "common sense." For example, appealing to certain cultural stereotypes, such as the psychiatrist being "madder than their patients" (Spandler 2020 p.129). In a similar vein, I would describe my *Asylum at Highroyds* zine as drawing on emotion as well as common experiential knowledge amongst survivors about: the fear associated with a (first) psych hospital admission; the disconnect between survivors' perceptions and staff perceptions; the intrusive and disempowering nature of surveillance; and the ambivalence we can feel about being discharged.

Although I think visually and tend to communicate visually and have found this a really useful way to contest psychiatric knowledge and practice, I chose not to carry out a practice-based PhD. This was because I didn't perceive creative practice as being valued in the way that non-creative practices are, and I wanted to engage with a process which I hoped might be perceived by others as having value. However, during the process of the research, it became increasingly clear that creative practices do have value, even where some audiences might not recognise this. The value of communicating with audiences who do value a person's own unique way of thinking and communicating also became clearer to me during the process of the research. Therefore, I use images throughout this thesis and I hope that readers will recognise and value the ways in which they represent my reflections, interpretations and understandings. As should become apparent, my use of images is in keeping with my findings and arguments, and is congruent with zines, as well as reflecting the process through which I reflect on, and articulate,

my experiences and findings. Because the images I use are integral to the text, they are not listed separately.

The research underpinning this thesis draws on interviews and workshops I conducted with survivors of the mental health system and some of the zines they created. It also draws on my own experiences as a survivor of the mental health system who has created and shared zines. Where I use direct quotes from survivors these are *italicised*. I do this as a way to recognise and highlight their contributions. For the same reason, I italicise the names of survivors' zines and name individual survivors or use a pseudonym according to their preference.

Madzines

I was recruited to undertake a survivor-led PhD about zines as part of a broader research project about radical mental health zines, the Crafting Contention ('MadZines') project, which was funded by the Wellcome Trust⁶. The broader project explored how Madzines might contest psychological, psychiatric and medical knowledge about madness and distress. It used the term Madzines to describe zines that include critical or challenging insights about mental health, which are usually created by people with lived experience of conditions that have been psychiatrised. My madzines colleagues and I worked together to explore how zines might generate and communicate alternative knowledge, swapping and discussing madzines and attending zine fairs together. However, once I had decided that my research would specifically focus on how and why survivors (can) use zines to address epistemic injustice, the wider Madzines project avoided focusing on this theme. In addition, the broader project situated itself more closely with Mad Studies, whilst my specific project is more aligned with survivor and arts-based research. This all helped to distinguish my thesis as an independent piece of research within the broader project.

Overview of Chapters

This rest of this thesis is comprised of eleven chapters. This thesis first sets the context for my research (chapters 1 and 2), then outlines how I went about it (chapter 3 and 4), then reflects on

Project website: www.madzines.org. Wellcome Trust Grant number: 219843/Z/19/Z "Crafting Contention: The role of zines in contesting mental health, knowledge and practice."

zines and zine making for combating epistemic injustice (chapters 5, 6, 7, 8, 9, and 10) and finally considers some limitations and ways forward (chapter 11).

In the first chapter I outline the barriers survivors face when trying to reflect on and articulate our experiences and/or share our understandings and experiences in the MH system. I also outline the opportunities that zines might afford survivors and identify relevant gaps in literature about survivors and zines. In the second chapter I introduce theories of epistemic injustice, explain how they have been applied to survivors, and how they might be useful for understanding survivors' experiences of making and sharing zines. In the third chapter I outline my survivor-friendly, zine centred methodology and methods. In the fourth chapter I introduce the research participants, and outline their zines, their zine making and sharing. In the fifth chapter I outline how the creative and crafty qualities of zines and zine making related to survivors' ability to reflect on and articulate their experiences. In the sixth chapter I outline how the flexibility of the structure of zines related to survivors being able to reflect on, articulate and share our experiences and understandings. In the seventh chapter I outline how readers responded to visual articulation, unusual and confusing structure and sculptural metaphors in zines. In the eighth chapter I outline the contexts in which survivors felt they had freedom and control over the content of their zines, and what choices they make about their audiences. In the ninth chapter I describe what the culture of the zine community can offer survivors including the way identity is conceptualised, the role of shame, the types of knowledge that are shared and valued and the way in which authority is established. In chapter ten I further develop my findings in relation to theories of epistemic injustice and agency. In chapter eleven I bring everything together in my conclusion and make suggestions for further research. I drew a map of the structure of the thesis on the following page which includes a key relating to the chapter numbers.

11

Survivors and zines: a literature review

This chapter will give an overview of two bodies of literature relevant to my thesis: survivors of the MH system and zines. First, I will outline existing literature about the various ways that survivors are constrained in being able to articulate, develop and share our understandings and experiences. I will follow this by outlining literature about zine-making and zines as a medium and literature about the community and culture in which zines are (often) shared. I will relate the literature about zines to the literature about survivors and identify gaps in relation to what we know about survivors and zines.

Survivors

In this section I will show that survivors' experiential knowledge is marginalized and constrained in multiple ways. I will outline literature about the devaluing of survivor knowledge, gaps in interpretive resources, and the impact on survivors of low (epistemic) confidence. I will also outline literature about the devaluing of subjective knowledge and literature about how unequal power dynamics between survivors and MH professionals can result in survivor knowledge not being shared or used. Much of the literature I write about in this section relates to survivors' experiences in the MH system.⁷

I will begin by focusing on literature which relates to where and how survivor knowledge is (or isn't) received and valued.

Devaluing survivor knowledge.

There is a wealth of literature about survivor testimony being devalued and not being perceived as credible, especially in health care settings and mental health services (Rogers and

⁷ Much of this literature doesn't delineate which part of the mental health system it is focused on, however where it refers to the dominance of biomedical models and/or the use of state sanctioned force then it might be described as referring to the psy system although as I outlined in my introduction, in practice there is a lot of crossover between the psy system and other parts of the mental health system.

Pilgrim, 1999; Grim *et al.*, 2019; Rose and Kalathil, 2019; Todd, 2021; Crichton *et al.*, 2017; Morant *et al.*, 2015; Hamilton *et al.* 2016; Bueter, 2021; Gosselin, 2018; Sanati and Kyratsous, 2015; Fisher, 2023). Much has been written about how mental health workers often dismiss service users' testimonies without making nuanced and graded credibility judgements of or about them (Grim *et al.*, 2019; Morant *et al.*, 2015; Crichton *et al.*, 2017; Todd, 2021; Rogers and Pilgrim, 1999; Sanati and Kyratsous, 2015). For example, Grim *et al.* (2019) found that people in receipt of mental health services are often stereotyped as "lacking judgment and decision-making capacity" (p.162); Morant *et al.* (2015) found that survivors insight and capacity for decision making is underestimated; Crichton *et al.* (2017) argue that being a survivor in receipt of services is linked with persistent stereotypes that negatively impact the way in which survivors are perceived as knowers; Sanati and Kyratsous (2015) describe how people with delusions are stereotyped as delusional about everything; and Rogers and Pilgrim (1999) have described survivors being treated as objects subject to the clinical gaze of psy professionals. In addition, Rose and Kalathil (2019) have written about survivors' knowledge not being perceived as legitimate; Hamilton *et al.* (2016) found mental health service users reported being stereotyped as not being credible in physical healthcare settings; Bueter (2021) has written about prejudices against 'the mentally ill' leading to "an unfair discrediting of their report of somatic symptoms" (p. 1136); Streslow (2010) has written about survivors' accounts of experiences of hospital not being trusted or believed; and Nash (2013) has written about survivors' accounts of physical health symptoms not being trusted or believed. Survivor testimonies attest to this credibility deficit (e.g. Todd, 2021; Lakeman, 2010).



Image 1.1 Not being seen as a knower

Some literature indicates that survivor knowledge may be perceived to be ‘non-sense’ or lacking in authority because of the unusual ways in which it can be structured. For example, Gee (1991) writes about a spoken account of a woman hospitalised for schizophrenia being given to him “as an example of a text that made little overall coherent sense to those who had collected it” (Gee, 1991, p.16). The woman’s narrative was not topic centred or temporally ordered but, by paying close attention to how it was put together and what it communicated via its unusual form (structure), Gee was able to understand what others saw as nonsense.

Reissman (2008) describes something similar in her analysis of male interviewees’ accounts of depression. Gee (1991) and Reissman (2008) show that if potential receivers of knowledge don’t allow themselves to be put off by unusual structures, they may find they understand what a person is trying to communicate and that the way a narrative is organised is actually part of the communication.

It is perhaps not surprising if testimony with unusual structures isn’t valued in the MH system or even if it is perceived as pathological because in the MH system non-linear thinking and experiencing is linked with psychiatric diagnoses. For example, non-linear memory is linked to the diagnosis of PTSD (APA, 2022; WHO, 2022; Halligan *et al.*, 2003); dissociation (which is also associated with non-linear memory) is seen as symptom of various psychiatric disorders (Engelhard *et al.*, 2003; Halligan *et al.*, 2003; Murray *et al.*, 2002; Kindt *et al.*, 2005); and Formal Thought Disorder (FTD) is used to describe what a clinician perceives to be disturbed

organisation and expression of thought and has been linked to diagnoses of Autistic Spectrum Disorder (Eussen, 2015), schizophrenia and bipolar disorder (Yalincetin *et al.*, 2017).

Although there is a wealth of literature about survivor knowledge being devalued, there is a need for more literature about the circumstances in which survivor testimony *is* in fact valued. In addition, the current available literature doesn't provide a lot of clarity about how the devaluing of survivor knowledge might be addressed, or whether the devaluing might be attributed to individual actions; a culture of devaluing survivor knowledge; the ways survivors are systemically and culturally conceptualised; the positions survivors hold in the MH system; or the relational dynamics between survivors and MH professionals. For example, whilst Sanati and Kyratsous (2015) suggest that "clinicians need to be aware of attributing delusional beliefs to patients too easily" (p.484) and Fisher (2023) suggests that professionals on the front line "are ideally placed to correct these injustices and amplify the voice of the service user" (p.1188) they don't specify how these changes might come about.

Other literature variously suggests a need for individual practitioners to change their practice; re-educating MH professionals; and systemic and/or cultural changes. For example, Grim *et al.* (2019) suggest that if professionals were to learn about the value of involving survivors as full epistemic collaborators this might lead to them being more open to valuing survivors as knowers. Crichton *et al.* (2017) call for psychiatrists to be trained to better listen to survivors and for wider social and political changes to how survivors are (or can be) perceived. Morant *et al.* (2015) recommend adopting processes that challenge established survivor and MH professionals' roles, which they say, "may require organizational and cultural shifts" (p.1012). Bueter (2021) argues that survivor testimony may be devalued due to "prejudice by an individual physician" or due to "structural features of the health care system" which cause the systematic deflection of survivor testimony (p.1152). Therefore, Bueter (2021) argues that, in addition to targeting physicians, there is a need to change "institutional features that promote structural

testimonial injustice” (p.1153). In other words, what may be needed are changes to the culture and relational dynamics, as well as changes to individuals’ actions.

Significantly, Todd (2021) calls for further exploration about which circumstances might enable professionals to value the knowledge survivors share with them, although Rose and Kalathil (2019) essentially suggest that they see the problem as so intractable within psy disciplines and MH services that they no longer engage with them.

Gaps in interpretive resources

To share our knowledge, survivors first need to be able to reflect on and articulate our experiences. In other words, we need what have been called hermeneutic or epistemic resources (Fricker, 2007; Dotson, 2012, 2014; Pohlhaus, 2012). I will refer to these as interpretive resources here because this term is more descriptive and accessible to survivors. Therefore, I will now focus on literature about the availability of interpretive resources, including which resources are recognised and valued, and how this affects survivors’ ability to reflect on and articulate our experiences.

For many years, survivors and researchers have highlighted the limitations of the conceptual tools with which survivors are expected to make sense of our experiences in mental health services (Shaw and Proctor, 2005; Shaw and Proctor, 2004; Slade, 2009; Morant *et al.*, 2015). More recently, literature has framed these issues in terms of epistemic injustice (Grim *et al.*, 2019; Hassall, 2022; Harper, 2022; Wodziński and Moskalewicz, 2023; Ritunnano, 2022). Epistemic injustice is an injustice that harms people’s ability to know about their lives and experiences and to be seen by others as knowledgeable. Fricker (2007) has described it as a form of injustice ‘done to someone specifically in their capacity as a knower’ (p. 1).

Some literature focuses on which interpretive tools are available, or most relied on, in the MH system and more widely for survivors to describe our experiences. For example, Ritunnano (2022) argues that survivors are disadvantaged when it comes to reflecting on and articulating

our experiences because our “access to hermeneutic resources is limited” and because our “interpretations are (systemically or particularly) dismissed” (pp.254-255). Other literature, for example, Grim *et al.* (2019) note that barriers to survivors articulating and sharing knowledge are most often related to dominant frames of interpretation that operate within the system, specifically medical/diagnostic framing. Whilst acknowledging some survivors find medical diagnosis and concepts useful, Grim *et al.* (2019) found that focusing on diagnosis often meant that mental health professionals didn’t show an interest in survivors’ own understandings and interpretations of their experiences, unless they fit with a diagnostic framing. Similarly, Hassall (2024) argues that survivors’ understandings and interpretive resources can be marginalised when clinicians frame our experiences in terms of psychiatric diagnoses and Harper (2022) argues that the dominance of medical narratives can make it difficult for survivors to be aware of and use other frames or interpretive resources. This can disadvantage us when we are trying to make sense of our experiences.

For example, Wodziński and Moskalewicz (2023) suggest that conceptualising autism in terms of deficit and/or inferiority, as the medical model does, can make it difficult for autistic people to understand themselves in different ways. They argue that autistic people’s interpretive practices and meaning making about their lived experience is hampered “when there are no other models for thinking of oneself than as a sick person or someone without a voice.”

(Wodziński and Moskalewicz 2023 p.5). Similarly, Shaw and Proctor (2004; 2005) argue that diagnosis can obscure the context of distress and the complexity of survivors’ experiences.

Not only are survivors disadvantaged by which interpretive tools are available, but the MH system is characterised by a culture of relying on interpretive resources created by and for professionals. For example, interpretive resources created by and for professionals are often seen as the *only* way of understanding and communicating an experience instead of one of many ways (Miller Tate, 2019; Scrutton, 2017; Grim *et al.*, 2019; Morant *et al.*, 2015; Slade,

2009; Le Blanc and Kinsella, 2016). Additionally, some literature suggests that if we don't interpret our experiences using the dominant interpretive resources in the MH system, we will be represented as possessing a lack of insight into our experiences (Amador and Kronengold, 1998; Geekie, 2004; Kirmayer and Corin, 1998; Rimke and Hunt, 2002). Essentially, this puts survivors in a 'catch 22' situation where we either use interpretive resources that might not work to describe our experiences, or we are perceived as unreliable knowers or contributors to knowledge.

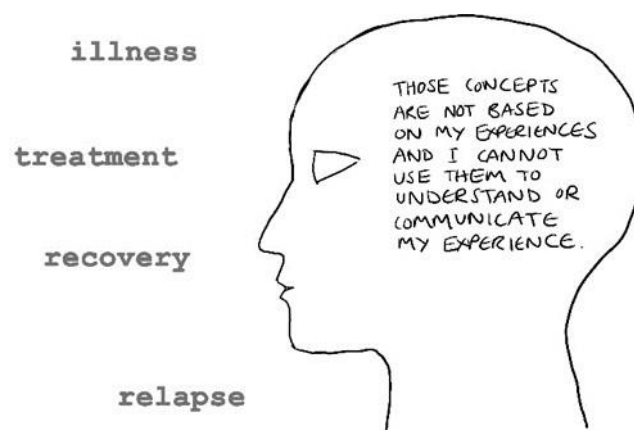


Image 1.2 Interpretive resources don't work

The available literature includes a variety of suggestions about how the difficulties survivors might have using diagnostic and medical frames to reflect on and articulate our experiences might be addressed. Some literature focuses on the need for survivors to have input into the development of medical and diagnostic framing; some call for individual, cultural and systematic changes to how and which interpretive resources are valued in the MH system; and some call for increased recognition of, and communication with, different epistemic communities.

Some of the literature suggests how survivors' difficulties might be addressed within the system of using diagnostic and medical frames. For example, some researchers suggest that the issue may in part be caused by survivors' lack of knowledge of these dominant resources, which

might be addressed by survivors gaining or being provided with more knowledge of the medical terminology and conceptual tools that MH professionals use (Grim *et al.*, 2019). Whilst other researchers suggest that problems caused by diagnostic and medical frames might be addressed by survivors being involved in the development of these conceptual tools used in the MH system including for example the development of the DSM⁸ (Kurs and Grinshpoon, 2018).

In contrast, Ritunnano (2022) describes how survivors' difficulties might be addressed by looking outside the system of diagnostic and medical frames. Ritunnano (2022) argues that clinicians need to recognise that survivors can and do interpret our own experiences and sometimes this involves using non-medical interpretive resources which clinicians should value and be open to. He goes on to argue that the difficulties survivors face in making sense of our experiences might be addressed within clinical encounters through things like professionals providing survivors with "alternative interpretive resources and tools (in linguistic or non-linguistic forms) produced by peers with lived experience of psychosis" and "alternative and creative methods for the articulation of ineffable experiences (e.g. visual, narrative and art-based methods of elicitation)" (p.255). In conclusion, he suggests that "structural remedies are needed to improve social integration between epistemic communities, and work towards greater hermeneutical equality and better representation of services users in mental health research" (p.258). Similarly, Harper (2022) and Grim *et al.* (2019) suggest that alternative systems of interpretive resources might help address survivors' difficulties. Harper (2022) argues that the difficulties survivors face might be addressed by survivor movements advocating for the use of alternative (non-biomedical) concepts and frames. He further argues that there is "a need for further research both documenting biomedical dominance and identifying how alternative frames can be introduced" (p.79). Whilst Grim *et al.* (2019) suggest professionals could use and validate "philosophical, emotive and idiosyncratic terminology that

⁸ The DSM is a book which outlines how different psy diagnoses are defined. It is created by and for psy professionals. It is used in the USA, Canada, Australia, New Zealand and the UK.

might support the service user in interpreting and articulating his or her illness experiences” (p.170).

There is some literature about interpretive resources that have been developed and used by survivors outside the MH system. However, there is a dearth of literature about the conditions in which it is possible for survivors to develop and use them. These interpretive resources include concepts like sanism⁹, the language of madness¹⁰, and hermeneutic tools like the unrecovery star¹¹. These conceptual resources were developed by mad activists and scholars to enable us to reflect on and articulate prejudice and discrimination against survivors (Le Blanc and Kinsella 2016); how social inequalities make people go mad and prevent recovery (Recovery in the bin, no date); and positive ways of perceiving oneself as a survivor/mad person (Beresford, 2019; Archibald, 2021). Le Blanc and Kinsella (2016) outline ways in which the concept of sanism enables survivors to articulate their experiences better than the more frequently used concept of ‘mental health stigma’ and suggest that it could be used as an interpretive resource to make visible survivors experiences of injustice, discrimination, abuse and oppression. Le Blanc and Kinsella (2016) point to Wolframe’s account of how discovering the concept of sanism enabled her “to find new interpretive resources to communicate her experiences” (LeBlanc and Kinsella, 2016, p.68). However, although these resources may benefit survivors, they are not widely recognised, used or valued in the MH system. For example, Le Blanc and Kinsella (2016) note that people experience sanism in “a culture in which the concept of sanism is not yet widely recognized” (p.68). However, in addition, some literature suggests that the limited availability of narrative templates, and narrow expectations of the narrative form, may also make it difficult for survivors to reflect on and articulate our

⁹ Sanism is a term developed to describe systemic discrimination against survivors. The term appears to have been coined by Morton Birnbaum in the 1960s (Perlin 1992).

¹⁰ Some survivors have reclaimed the term mad as a positive identity (Beresford 2019, Archibald 2021) and Mad Studies as a field has evolved in part to centre the oppression of mad people and mad people’s knowledge and perspectives (Gorman and LeFrançois 2017).

¹¹ The unrecovery star is a tool developed by survivors in a Facebook group called Recovery in the Bin.

experiences (Woods, 2011; Woods *et al.*, 2022; Donnelly, 2021; Ingram, 2016). For example, Woods *et al.* (2022) argue that survivors are often required by mental health providers to use recovery as a narrative template within which we must articulate our experiences, and this limits what we can articulate because narrative templates tend to be linear and temporally organised. Woods (2011) has highlighted the limitations of linear temporally ordered sensemaking and argues that we need to consider ways in which people might experience their lives beyond this. Donnelly (2021) suggests that in the west we rarely see accounts of illness or disability that diverge from what Arthur Frank (2013) has described as 'restitution' or 'quest' narratives, precisely because we expect articulation to be in a linear and emplotted form. Mad Studies scholar Ingram (2016) has written about the limitations of the narrative form in relation to his own process of thinking and relaying his (mad) thoughts. He argues that Mad Studies should call for, or create, changes to what is recognised and valued as knowledge and sensemaking, including questioning the value of what he calls 'coherence'.

Low epistemic confidence

A few researchers have suggested that survivors may find it difficult to reflect on and articulate our experiences due to having low confidence in our ability to do so (Scrutton, 2017; Hassall, 2022; Björk Brämberg *et al.*, 2018). This has been related to the dominant interpretive resources not working for survivors, and survivors being conceptualised and treated as incapable of making sense of our experiences. For example, Scrutton (2017) suggests that being required or expected to use psychiatric concepts to make sense of our experience when these don't fit might result in us losing confidence in our own interpretations. Hassall (2022) argues that receiving a psychiatric diagnosis can cause survivors to have less trust in their own judgements and interpretations especially where these seem to conflict with the judgment of a clinician. Björk Brämberg *et al.* (2018) found that survivors' previous experiences of not being believed and not being taken seriously, combined with their own thoughts about madness/mental illness, sometimes made them doubt whether their somatic symptoms were 'real'. In other

words, their epistemic confidence was so low that even in the face of physical symptoms telling them there was something wrong in their own body, they felt unable to interpret this according to their experience, but instead felt compelled to go along with medical professionals' disbelief and depreciation.

Survivors' low confidence may also be due to lack of interpretive resources with which we might conceptualise ourselves as capable epistemic agents. Some literature suggests that survivors are perceived entirely or primarily in terms of their mental health status in the MH system (Rogers and Pilgrim, 1999; Grim *et al.*, 2019; Todd, 2021; Rose and Kalathil, 2019; Hassall, 2022). This is significant in relation to survivors' confidence because, if we are in an environment in which we are perceived in this way, we may struggle to see ourselves outside this status and the prejudicial stereotypes associated with it, which include our inability to reflect on and articulate our experiences. There is limited research about circumstance in which survivors might have or gain confidence in our ability to make sense of our experiences.

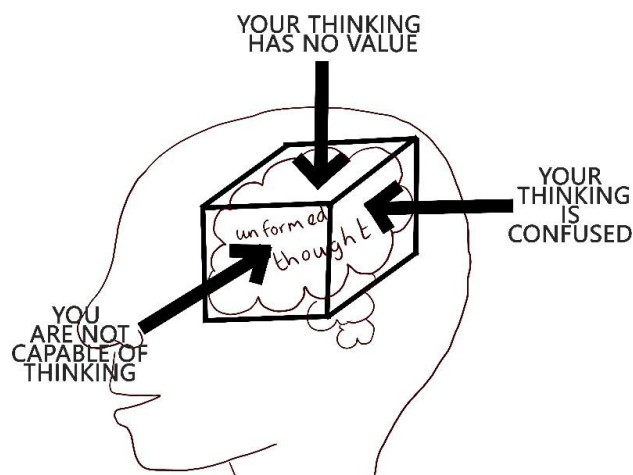


Image 1.3 Epistemic confidence

Devaluing subjective knowledge

Some literature suggests that survivors may be epistemically disadvantaged by the underlying ontology and epistemology, as well as cultural beliefs about objectivity, absolutism and

universalism, in the MH system (Crichton *et al.*, 2017; Carel and Kidd, 2014; Scrutton, 2017; Rose and Kalathil, 2019; Florsheim, 2020; Jackson, 2017). For example, Crichton *et al.* (2017) have stated that 'hard' and 'objective' evidence is highly valued in the MH system as opposed to subjective experience. They note that although it has been argued that "medicine is not itself a science but rather an interpretive practice" and "in psychiatry, there is virtually no hard evidence" the MH system remains focused on evidence which is perceived to be hard or objective (Crichton *et al.*, 2017, p.67). They argue that this disadvantages survivors because this type of evidence may only be available to health professionals and the 'soft' or subjective evidence survivors use is devalued by professionals. Carel and Kidd (2014) argue that patients who draw upon subjective experiences in their reflective sensemaking process can find their interpretations judged as irrelevant or insufficiently accurate because subjective experiences are not recognised or valued as contributions to knowledge (see also Scrutton, 2017). Scrutton (2017) argues that epistemic injustices in psychiatric healthcare "are founded on and perpetuated by the prioritization of objective, third-person accounts to the detriment and even exclusion of subjective, first-person ones" (p.353).

Some literature indicates that survivors might be disadvantaged by beliefs about objectivity, absolutism and universalism in the MH system. For example, Florsheim (2020) argues that the search for objectivity in the MH system means that it goes unrecognised that "defended conceptions are always possible interpretations of the world" (p.9). In other words, it isn't acknowledged that there are other ways that we might interpret madness. He also argues that cultural, theoretical and individual subjectivities "are neglected in the name of a supposed objectivity of knowledge" (p.9). This, he argues, makes it difficult or even impossible to recognise the value of alternative models or conceptualisations, even though different explanatory models do not necessarily exclude each other. Similarly, Florsheim (2020) and Rose and Kalathil (2019) have linked the MH system to universalism, leading to cultural differences only being "considered on a superficial level" (Florsheim 2020 p,4). Universalism is the

idea/belief that human experience is similar across cultures and that norms, values and concepts (and the practices that are based on them) can be applied everywhere without modification. Rose and Kalathil (2019) have argued that calling professionals' knowledge 'scientific' is a way to deny or make invisible the political nature of this knowledge, whilst devaluing survivor research. In other words, there may be a culture of relying on/claiming objective knowledge and an associated belief in universalism in the MH system which may disadvantage survivors and make it difficult to know about specific individuals' contextual experiences and intersectional knowledge. Put another way, the perception that MH professionals' knowledge is (more) objective and survivor knowledge is subjective may be used to devalue survivor knowledge and obscure the subjective nature of professionals' knowledge.



Image 1.4 Beliefs about knowledge in the MH system

Power dynamics between survivors and mental health professionals

Much has been written about the ways in which MH professionals have power over survivors in the MH system (e.g. Foucault, 1965; Bracken & Thomas, 2001; Hannigan & Cutcliffe, 2002; Heffern & Austin, 1999; Szasz, 1994; Walsh *et al.*, 2008). Recognising the ways these power imbalances relate to the production of knowledge and the available resources for

understanding survivors' experiences has been described as crucial if survivors are to have any hope of experiencing epistemic justice (LeBlanc and Kinsella, 2016; Kinsella & Whiteford, 2009).

Some literature indicates that professionals' position in the MH system means they decide who can share what knowledge, when, where and how (Crichton *et al.*, 2017; Rose and Kalathil, 2019; Peck *et al.*, 2002; Grim *et al.*, 2019; Tobin *et al.*, 2002). The control that MH professionals have over knowledge in the MH system is reflected in the way Crichton *et al.* (2017) refer to the necessity for psychiatrists "to *allow* patients to have a greater epistemic role" (Crichton *et al.* 2017, p.70 my emphasis). Rose and Kalathil (2019) write about this in terms of professionals using their position to veto what can be said or enacted. In their study of mental health services in England, Peck *et al.* (2002) found much survivor involvement could be best be described as consultation i.e. the agenda was already set by mental health professionals. Grim *et al.* (2019) also found that survivors were not able to add issues to the agenda and reported that survivors described professionals excluding them "from deliberative conversations and decision making" (p.164). Similarly, Tobin *et al.* (2002) found survivors often didn't participate in decisions about their treatment or in service development activities because professionals didn't offer them the opportunity or invite them to do this. Some researchers describe how the testimony of survivors is especially marginalised because of the failure to address intersecting systems of inequality, within participatory community interventions (Cooke and Kothari, 2001); mental health service involvement (McDaid, 2009); and mental health peer support provisions (Faulkner, 2017; Faulkner & Kalathil, 2012).

These power dynamics have also been linked to survivors having very little control over how their knowledge and understandings are recorded or (mis)used. For example, Grim *et al.* (2019) found survivors had little or no control over how their experiences were interpreted, or how their difficulties are "conceptualised, categorized and documented" (Grim *et al.*, 2019, p.166). They also found that survivors felt unable to protect themselves from professionals' prerogative to

dismiss and misinterpret their contributions (ibid: p.167). None of us can prevent ourselves being dismissed or misinterpreted, but when the person doing this is in a position to control what is documented and accepted as knowledge about us, survivors are at a particular disadvantage.

Some literature suggests survivors don't share knowledge in the MH system because of the vulnerability of their position in relation to MH professionals (Rose and Kalathil, 2019; Grim *et al.*, 2019; Laugharne *et al.*, 2012). Rose and Kalathil (2019) write that the "deeply unequal" power dynamics between survivors and MH professionals prevented survivors from sharing testimony (p.2). Grim *et al.* (2019) found that survivors described "staying silent or editing (the) communication due to imbalances of power" and "being silent or editing... testimonies" because they feared "negative consequences" (p.163). Specifically, Grim *et al.* (2019) found that survivors often thought it would be futile saying what they really thought and edited their communication in an attempt to get professionals to listen or to avoid being disliked by mental health workers and having their care and support withdrawn (Grim *et al.*, 2019, p.163). Similarly, Laugharne *et al.* (2012) found that threats of psychiatric coercion and/or neglect made survivors feel unable to speak up or contribute to decision making.

Some literature suggests that power imbalances in the MH system lead to the silencing of knowledge, which is critical of, or differs from, that of MH professionals. Some researchers have suggested MH professionals don't welcome knowledge which they perceive to be challenging them, or their position, and often perceive survivors' knowledge in this way (Lindow, 1999; Omeni *et al.*, 2014; Felton & Stickley, 2004; Grim *et al.*, 2019).

Omeni *et al.* (2014) have written about professionals perceiving survivor criticisms as unwarranted and unconstructive. Lindow (1999) suggests that survivors "justifiably angry demand(s) for rights" are seen as "a sign of mental illness or 'acting out'" (p.165).



Image 1.5 Survivors experiences in the MH system

It has been suggested survivors might benefit from alternative ways of knowing and alternative ideas about what can be known that are more commonly found outside the MH system. For example, some researchers have called for the use of a subjectivist epistemology and a phenomenological approach (Carel, 2012; Ritunnano, 2022; Parnas *et al.*, 2013; Jackson 2017). Ritunnano (2022) argues that using critical phenomenology “is a step towards overcoming hermeneutical injustice in mental health” (see also Parnas *et al.* 2013). Writing about depression, Jackson (2017) argues that phenomenology is essential to combatting epistemic injustice and links this with empathy.

There is a wealth of literature about how survivors use creative methods to make sense of experience in therapeutic settings (e.g. Beaumont, 2013; Ford *et al.*, 2021; Echard, 2019) and about the use of creative methods in research (e.g. Mannay, 2015; Kara, 2020; Young, 2018). Despite this, very little has written about how access (or lack of access) to creative sensemaking methods and processes might enable (or prevent) survivors’ ability to reflect on and articulate their experiences *outside* of therapeutic settings.



Image 1.6 Visual and pattern sensemaking vs cultural expectations

In addition, some literature indicates that being able to use visual methods or create patterns may be especially important for neurodivergent survivors. For example, Grandin (2022) has linked neurodiversity to different types of sensemaking, specifically suggesting that people who are neurodivergent often process information through pictures, patterns and spatial relationships and are disadvantaged by being expected or required to process information verbally. Given that survivors are more likely to be neurodivergent than the general population¹², we may particularly benefit from opportunities to make sense of our experiences using visual methods and methods that enable us to map out our thoughts. If survivors don't have these opportunities, we may be epistemically disadvantaged. However, there is currently limited literature about this.

However, there is some literature that indicates the cultural bias against the use of creative sensemaking tools can hinder the understanding of patients' subjective experiences in *general*

¹² There have been shown to be high rates of autism in and ADHD amongst adult psychiatric outpatient clinic patients compared to the general population (Nyrenius et al 2022, Syed et al 2010 and Rao and Place (2011). Autistic people are more likely than the general population to be diagnosed with psychiatric conditions (Lai et al., 2019) and Autism and ADHD themselves are diagnosable disorders in the DSM-5 (APA 2022).

healthcare settings. For example, Carel and Kidd (2014) directly relate access to creative sensemaking methods to who might be able to reflect on, articulate and share what knowledge, suggesting that “the structures of contemporary healthcare practice encourage epistemic injustice because they privilege certain styles of articulating testimonies, certain forms of evidence, and certain ways of presenting and sharing knowledge” (p.530). In other words, creative methodologies and creative ways of articulating and sharing testimony are devalued in health care systems. Elsewhere it has also been suggested that the use of creative and sensual tools in healthcare research, including images and sound, can enable new understandings to be developed, understandings which are based on experience and perception instead of “already formulated ideas” (Carel, 2012, p.109). Carel (2012) further suggests that the use of these creative and sensual tools can enable people “to explore possibly unnamed emotions and experiences” (p.109).

Survivors: summary

In summary, there is a wealth of literature which indicates that survivor knowledge is marginalised in a myriad of ways which has been related to the culture and power dynamics in the MH system where survivors are not seen as credible knowers. This includes the culture of conceptualising survivors in terms of our mental health status, not valuing survivor developed concepts, relying on epistemologies, ontologies and sensemaking methods which disadvantage survivors, and perceiving and treating survivors as untrustworthy contributors of knowledge. It includes professionals not inviting survivors to share their knowledge and re-interpreting or not recording what survivors tell them and survivors not sharing knowledge because of the vulnerability of our position in the MH system. However, there is little literature about the circumstances in which survivor knowledge or survivor developed concepts are/might be recognised and valued.

Specifically, despite there being indications that it might benefit survivors to articulate and share knowledge away from the MH system, there is very little literature about this. In addition,

despite there being indications that survivors might benefit from being able to reflect on, articulate and share experiences using visual, non-linear and sensual forms/methods there is very little literature about this happening outside of therapeutic settings. Zines might be one way that survivors can reflect on, articulate and share our experiences. Therefore, in the following section I will outline relevant literature about zines and relate this to the literature about the marginalisation of survivor knowledge and survivors as knowers.

Zines

This section will begin by outlining literature about what and whose knowledge gets shared via zines. I will then outline literature about zines and zine-like mediums and then literature about the community in which zines are often shared, including the culture of the zine community.

When I use the term ‘zine-like medium’ I mean graphic media, specifically texts that are created by a single person using a combination of words and images, what Spiegelman has termed “picture-writing” and Satrapi has called “narrative drawing” (cited in Chute, 2010, p.6) or texts that are entirely image based. Although some zines are entirely text based, many also include images, and I will focus on these because as I outlined in the previous section the use of images may be especially important for survivors.

Whilst the relationships between zines, the zine community and zine culture are complex, I structure this section in this way so I can contrast the literature on zines with the literature about survivor knowledge and the MH system.

Zines and marginalised knowledge

There is a great deal of literature about the culture of sharing marginalised knowledge and counter-narratives in zines (Clark-Parsons, 2018; Piepmeier, 2009; Duncombe, 2017; Knobel and Lankshear, 2002; Chidgey, 2006; Congdon and Blandy, 2003). Knobel and Lankshear (2002) have described zines and zining practices as determinedly non-mainstream; Chidgey (2006) has said zines circulate “on the margins of print and academic cultures” (p.1); Congdon and

Blandy (2003) have written about zines offering critiques of society; and Keaton (2019) has written about people sharing stories of resistance via zines. Piepmeier (2009), Duncombe (2017), Clark-Parsons (2018), and Keaton (2019) have all written about zines being used to share knowledge created by and for activist communities. In addition, there is literature about graphic media being used as a medium for campaigning and sharing the voices of people who might not otherwise be heard (Robbins, 2013; Chute, 2010; Spandler, 2020).

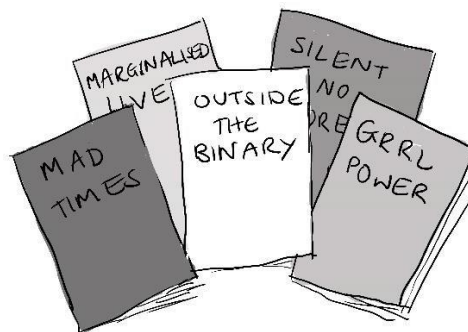


Image 1.7 Marginalised knowledge in zines

Zines are often used by marginalised people including, survivors, women, queer, trans and non-binary people to articulate and share knowledge. For example, there is literature that focuses on women articulating and sharing knowledge via zines (Piepmeier, 2009; Dudley Shotwell 2016; Bates and McHugh, 2014; Chidgey, 2006; Guzzetti and Gamboa 2004). Some link this with the riot girl movement (e.g. Piepmeier, 2009), resisting mainstream discourse (Ferris, 2001), feminism (Bates and McHugh, 2014; Chidgey, 2006), and social justice (Guzzetti and Gamboa, 2004). There is also some literature about non-binary and trans people using zines in a similar way, including black queer women and non-binary people using zines to articulate and share their experiences (Daniels, 2022), and queer and trans people using zines to resist pathologizing narratives (Latham and Cooke, 2020) and the representation of non-binary identity in zines (Mahr, 2018). Conversely, Reynolds (2019) has drawn attention to the whiteness of zine culture, the lack of inclusion of zinesters of colour and the fact that it takes time and money to create and share zines.

There is some literature that is about, or at least touches on, survivors articulating and sharing knowledge via zines (Cameron, 2012; Eisenhauer, 2010; Delmée, 2020) including outputs from the wider project of which this thesis was a part¹³. This literature hasn't extensively explored how the qualities of zines, zine community or the culture in which zines are shared might enable survivors more broadly to reflect on, articulate and share experiences and/or have our knowledge valued and it hasn't related this to the multiple difficulties/barriers survivors experience when it comes to reflecting on our experiences, articulating and sharing our understandings and having these appropriately valued. For example, Delmée (2020) writes about the understanding and knowledge survivors share in their zines, specifically how survivors use theory in their zines to "articulate their multiple identities in complex ways" (p.57) but he doesn't specifically explore how or why they do this in/through zines. Meanwhile Eisenhauer (2010) argues that, through sharing zines that critique medical discourses and stigmatising popular media portrayals of mental illness, survivors create community, form connections with others and subvert experiences of confinement. Eisenhauer (2010) also suggests that by sharing autobiographical zines about madness, survivors are "challenging who is deemed to be the legitimate voice for an illness" (p.36) and reclaiming "lost agency" (p.34). However, like Delmée, she writes very little about how qualities of zines and/or the community and culture in which zines are shared, might enable survivors to create and share these accounts and understandings.

In her PhD thesis, Cameron (2012) uses a narrative arts-based methodology to explore how "young women narrate experiences of "depression" as education" and how zines enable this topic to be explored "as embodied, emotional and critical transformative learning" (p.ii). The women in her study were between the ages of 29 and 40, had all experienced depression in their early 20s and were all raised and lived in rural Nova Scotian communities. Whilst Cameron

¹³ www.madzines.org

does relate survivors' processes of reflecting on, articulating and sharing their experiences to the qualities of zines, she does not relate these to the communities in which zines are often shared or the cultures of these communities. Cameron (2012) focuses on what she calls the '*seamful*' nature of zines, focusing on how being unfinished, unpolished and loosely assembled, zines might create space for community understanding and enable survivors to engage in meaning-making based on their lived experiences. Cameron (2012) argues that the seamfulness of zines is accessible to zinesters and zine readers and creates space for uncertainty and ambiguity which enables survivors to use zine-making to work through feelings, thoughts, and events, write from lived experience and imagine alternative perspectives or ways of understanding their experience. She also suggests this seamfulness affirms embodied, community-based knowledge and invites readers into a personal relationship with in which they might empathise with zinesters. Whilst Cameron (2012) usefully locates survivors making and sharing zines within the context of cultural, literary and psychiatric accounts of depression in America, she doesn't explicitly relate it to the multiple ways in which survivor knowledge and survivors as knowers are marginalised.

Zines, zine-like mediums and survivor knowledge

In this section I will focus on literature which explores how the qualities of zines and zine-like mediums enable reflection, articulation and/or the communication of knowledge.

Articulating knowledge

In terms of zines, Cameron (2012) describes zine-making as "a labour of love that invites the maker to devote focused attention on a particular topic, whether for an afternoon or over several months" (p.262). She describes zine-making as a process of reflection and articulation, although it may not always be recognised as such. Creating narrative is widely recognised as a process of reflection and articulation, however narratives are commonly expected to be linear and word based (Bruner, 1986; Frosh, 2017). The same cannot always be said for zines or other zine-like media. For example, Said (2005, cited in Whitlock 2006) suggested that because

comics move beyond traditional narrative forms, they can enable their creators to “think and imagine and see differently” (p. 967).

As I have previously touched on, Cameron (2012) has argued that the fact that zines are not always finished and polished, or straightforward to read, can help complexity, contradictions and uncertainties to be articulated and shared (Cameron, 2012). Cameron (2012) writes that “zines tell us, we don’t need to express logical, irrefutable, black and white certainties” (p.263-p.264). This contrasts with the difficulties I have outlined in the MH system, where knowledge is often perceived as absolute and universal, and only valued if it perceived to be objective or scientific.

In addition to literature which describes making zines as a reflective process, there is some literature which links qualities of zines and zine-like mediums to what people can share and who therefore might benefit from sharing knowledge via zines. For example, some comics scholars have suggested sharing traumatic experiences may be supported by the visual and non-linear qualities of zines (Chute, 2010; Earle, 2014, 2019). Similarly, Chute (2010) and Earle (2014, 2019) have suggested that use of non-linear structures and visual symbols can be particularly advantageous for sharing accounts of trauma. Chute (2010) has written about this in terms of comics creators using the formal techniques of the comic to mimic traumatic experiences and Earle (2014) refers to people being able to represent trauma through comics via “mimicking the shattered chronology of a trauma narrative” (p.1). This is important because of the well-established relationships between trauma and mental health system survivors.¹⁴ That zines have a non-linear quality is significant because, as I outlined in the previous section, opportunities to articulate experiences in non-linear forms are often unavailable in the MH

¹⁴ People in the MH system are more likely to have histories of trauma (Center for Substance Abuse Treatment, US 2014); people who have experienced trauma are more likely to experience psychological symptoms and receive a psychiatric diagnosis (Center for Substance Abuse Treatment US, 2014²; Magruder *et al.*, 2017); having experienced trauma may increase the severity of psy symptoms; and people with a psychiatric diagnosis are at a higher risk of experiencing trauma (Center for Substance Abuse Treatment US, 2014).

system, and non-linear accounts can be devalued, perceived as non-sense or pathologised in the MH system, all of which may particularly disadvantage survivors. Notably Cooper (2021) writes that in zines they discovered “space for the complicated, nuanced, non-linear and situated experiences of madness, mental health services and ‘recovery’”.



Image 1.8 Articulating and sharing experiences of trauma or pain via graphic media

Some literature suggests that the more embodied and visual qualities of the zine-making process can help people reflect on and share their experiences. For example, Cameron (2012) and El Refaie (2019) have written about the advantages of being able to participate in an embodied process of reflection and articulation. Cameron (2012) wrote this of her own zine-making: “the act of making the zine enabled me to feel more connected to the subject matter and express it in a more visual way” (p.203). She linked this to valuing diverse ways of knowing and has argued that zine-making “acknowledges that our bodies know beyond words” and “emotions are forms of knowledge that transcend and disrupt our Western reliance on words” (p.208). Cameron (2012) and El Refaie (2019) also both suggest that being able to use images in zines and zine-like media is helpful for articulating and sharing painful experiences (Cameron, 2012; El Refaie, 2019). El Refaie (2019) has written about this in terms of people being able to represent the body or the sensation on the page in graphic media, whilst Cameron (2012) suggests being able to use images and metaphors in zines can “enable creators to gesture

towards painful experiences without having to spell them out...to show, rather than tell” (, p.261). As experiences of madness (and being in the MH system) can be traumatic and painful, this may be particularly important for survivors. More generally the idea that the embodied and visual qualities of the zine-making process can be helpful for reflecting on and articulating experiences may be particularly useful to survivors. As I outlined in the previous section, whilst survivors may especially benefit from opportunities to make sense of our experiences using visual methods and methods that enable us to map out our thoughts, it has been argued there is a bias against the use of creative and sensual sensemaking processes in health care research (Carel and Kidd, 2014; Carel, 2012).

Receiving knowledge

There is also literature which relates the qualities of zines and zine-like mediums to how readers receive knowledge. This includes literature that suggests the non-linear, visual art based and sculptural qualities of some zines and zine-like mediums can affect and actively engage readers, enabling them to receive knowledge in more embodied ways. For example, Chute (2010) argues that, in graphic media about trauma, the use of non-linear chronology may lead the reader to experience in some part the disturbance that is being articulated. In other words, the knowledge is not confined to the content and so it can be received in more embodied ways. This resonates with what Cameron (2012) writes. about how arts-informed texts invite people to engage with subject matter through their “minds, hearts and bodies”, leading to “embodied empathy, the imaginative capacity to see as another” (p.209). Frank (2016) and Chute (2010) have suggested that when texts aren’t straightforward the reader may have to be more active when reading them in order to make sense of what they are reading. In relation to graphic narratives, Chute (2010) writes that readers must be active in the process of making meaning through the space between the text and images, whilst Frank (2016) draws attention to the need for readers to make decisions about which panel to read next and consider in what way panels might be connected.

Piepmeyer (2008) argues not only that the visual elements of zines are essential to what zines can communicate, but also that the sculptural elements can change how the knowledge is received. She gives the example of a reader having to untie a fastening that has been tied onto the zine by the zinester in order to read it. She suggests that this results in the reader feeling like they are being taken into the zinester's confidence and invited to be an ally to their experience. Being invited to immerse themselves in the knowledge being shared and engage with it with their mind, body and soul, directly contrasts with the literature I described in the previous section about the valued interpretive resources, methods, ontology and epistemology in the MH system. In the latter, survivors' experiences tend to be observed and evaluated from the outside, using diagnostic categories.



Image 1.9 Sculptural elements trust and allyship

Some researchers have argued that the physical and handmade qualities of zines create a sense of intimacy and connection between zinesters and zine readers (Triggs, 2010; Cameron, 2012; Piepmeyer, 2009; Watson and Bennet, 2021). Triggs (2010) argues that zines derive an intimacy through being “amateur, ‘handmade’ productions operating outside mainstream publishing conventions and mass-production processes” (p.206). Piepmeyer (2008) suggests that the “scrappy messiness” of many zines helps create intimate and affectionate connection between zine creators and readers (p.222). She also argues that the physical quality of zines mean they provide a kind of “bodily surrogate, that leads to intimacy, connectedness” (ibid:

p.224). Piepmeier (2009) notes that her students “gravitate toward zines that are visibly different from magazines and other mainstream publications, either by virtue of size or hand-coloured drawings or their sheer unprofessional appearance” (p. 57). Piepmeier (2008) also suggests that amongst zine creators there is a belief that “paper is better suited to facilitating human connection than electronic media” (p.220). Watson and Bennet (2021) write that “readers are immersed in the content/form and moved to participate in the bodily act of reading through the tactility and materiality of the DIY form” (p.131). They also argue that the textures and sensory affordances of zines heighten a sense of intimacy for readers and increase their effect on readers. This sense of personal intimacy and connection is very different from anything described in the literature about survivors and the MH system.

Zine community and culture

In this section I will outline literature about the dynamics and culture of the communities in which zine are often shared. I will relate this to what is/can be reflected on, articulated, shared and valued.

There is a wealth of literature which relates zines to the idea of community although, apart from Cameron (2012) and Cooper (2024), this has rarely been related to MH system survivors.

Literature about the spaces in which zines are shared indicates that zines are shared in/between communities of peers (Duncombe, 2017; Piepmeier, 2009). Duncombe (2017) has described zines as more like a clubhouse or community and suggests that the aesthetic of zines both reflects this and positions readers as friends and equals, and Piepmeier (2008, 2009) described zines as ‘embodied community’. Cooper (2024) writes about how zines by survivors and other sick and disabled people “constitute bed as a site of community” (p.102). There is also a wealth of literature connecting zines with a DIY culture of participation (Duncombe, 2017; Piepmeier, 2008, 2009; Watson and Bennet, 2021; Cameron, 2012; Triggs, 2010). For example, Duncombe (2017), Piepmeier (2008, 2009), and Triggs (2010) all argue that zines both exist within a participatory DIY culture and also represent and create this culture. Duncombe

(2017) refers to zinesters creating culture rather than consuming it, and Piepmeier (2009) has called zines a participatory media. Duncombe (2017) and Piepmeier (2008, 2009) have written about the DIY approach to cultural production being reflected in and enacted through the handmade process and aesthetic of zines. Watson and Bennet (2021) and Cameron (2012) have connected the homemade aesthetic of zines with zines evoking “the value of DIY cultural practice” (Watson and Bennet, 2021, p.128), and serving as an affirmation of “embodied, community-based knowledge” (Cameron, 2012, p.262). Piepmeier (2009) and Triggs (2010) have argued that the amateurish methods used to create zines, and the unpolished aesthetic of zines serves to call people to participate in zine-making and Eisenhauer (2010) notes that “Zinesters include their own mailing and email addresses in their zines and encourage those that read their work to dialogue with them” (p.27).



Image 1.10 Zine culture

Zines have been linked to a culture of exchange and non-commercialisation (Duncombe, 2017; Piepmeier, 2008, 2009; Richardson, 1996; Liming, 2010; Knobel and Lankshear, 2002; Cameron, 2012; Watson and Bennet, 2021). In turn, this culture has been linked to people participating in making and sharing zines feeling free to focus on the message they want to articulate and communicate, and zines being received as gifts. Richardson (1996) has written about people

making zines so they could trade these as a way of getting more zines. Knobel and Lankshear (2002) suggest that because zinesters and zine readers aren't subject to commercialisation, they can read and write the world as they see it without this being co-opted, and Cameron (2012) has written about how, in zines, self-expression and education are prioritised above mastery and profit. Piepmeier (2008) has argued that because zines are made as acts of pleasure and generosity, instead of attempts to gain power or prestige, they are more likely to be received as gifts.

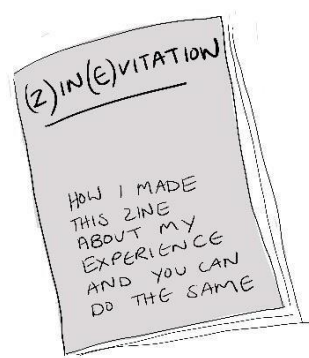


Image 1.11 Zines and participation

The available literature suggests that zine culture values knowledge based on lived experience (Duncombe, 2017; Liming, 2012; Chidgey, 2006; Poletti, 2008; Sinor, 2003). Perzines defined as "personal diaries open to the public; shared notes on the day-to-day life, thoughts, and experiences of the writers" (Duncombe, 2017, p.14) are the most common category of contemporary zines (Liming, 2010) and a growing number of studies have focused on zines as sites for autobiography and life-writing (Cooper, 2024; Chidgey, 2006; Poletti, 2008; Sinor, 2003).

This culture is in direct contrast to the unequal power dynamics prevailing in the MH system which tends to focus on knowledge that is perceived as objective at the cost of devaluing survivor accounts based in lived experience. Therefore, there is scope to explore how this culture of valuing lived experience relates to survivors articulating and sharing our knowledge.

Although they haven't been written about in these terms, you could argue that zines embody and represent a culture of taking a phenomenological approach to knowledge. Watson and

Bennet (2021) have argued that zines represent a way of “orienting toward, creatively engaging with and experiencing the world” (p.146). Cameron (2012) writes about zine-making as being a methodology that “acknowledges that our bodies know beyond words [where] emotions are forms of knowledge that transcend and disrupt our Western reliance on words” (p.208).

Ptolomey (2020) has said that one of the reasons she chose to do zine-making with her research participants is that she wanted to create space for the unexpected, to look at process and meanings instead of accessing pre-formed opinions or gathering data on people’s perspectives. She suggests that sticky, exploratory, slow, tactile methods like zine-making can create room for the unexpected (Ptolomey and Nelson 2020). As I outlined in the previous section, there is evidence to suggest that the MH system epistemically disadvantages survivors, and it has been argued that we might benefit from taking a more phenomenological approach.

Zines: summary

I have outlined literature about the qualities of zines and zine-like media and related this to the literature about the multiple difficulties/barriers survivors experience when it comes to reflecting on our experiences, articulating and sharing our understandings and having these appropriately valued. I have also outlined literature about the community and culture in which zines are often shared, and contrasted this with what literature tells us about the structure and culture of the MH system. I have shown that zines and zine-like media, and the zine community and culture have qualities which may benefit survivors when we try to reflect on our experiences, articulate and share our understandings and have these understandings appropriately valued.

I have also shown that whilst there is wealth of literature about marginalised (peoples) knowledge being shared in/via zines there is very little literature about survivor knowledge being shared via zines. The most relevant study about survivors’ zines focused specifically on Nova Scotian women and uses a narrative-based and arts-informed inquiry to explore how zines allowed them to narrate experiences of depression as education and learning (Cameron, 2019).

Cameron's study framed survivors' zines in terms of pedagogy and related survivors' narration to the qualities of zines, but not to the community and culture in which they are shared. It located their experiences within the context of wider medical and cultural narratives, but not in relation to the multiple barriers survivors face when it comes to reflecting on our experiences, articulating and sharing these and having them appropriately valued.

Gaps in literature and scope for research

My review of the literature suggests that there is a need for more literature about the circumstances in which survivor testimony is valued; the conditions in which survivors might develop interpretive resources; the circumstances in which interpretive resources that are developed or favoured by survivors are valued; and the circumstances in which survivors might have or gain epistemic confidence.

There is also a lack of literature about why survivors might use zines to articulate and share our understandings. For example, there is limited literature linking survivors' experiences of creating and sharing zines to the multiple barriers survivors face when it comes to articulating and sharing our experiences and having our understandings and testimony appropriately valued. In addition, there is a lack of literature about whether, or how, the qualities of zines, the zine community and/or zine culture might enable survivors to articulate and share their experiences and have this knowledge valued.

Therefore, there is scope to explore how zines and the community and culture in which they are shared might enable survivors to reflect on and articulate experiences and share their understandings and have them appropriately valued. There is also scope to explore whether zines might be a way for survivors to take a more phenomenological approach to knowledge and in what ways that can help or hinder us to articulate and share knowledge. Finally, there is scope to explore how the zine community, with its culture of participation exchange and non-commercialisation, might affect what survivors are able to reflect on, articulate and share,

especially in relation to their criticisms of MH professionals and the MH system, which can be especially difficult for survivors to share in the MH system.

The following chapter will outline some of the relevant theories and concepts underpinning this research. It will include different accounts of epistemic injustice and theories about how knowledge production and sharing can be limited as well as theories about how this might be addressed. It will also outline where and how these theories have been related to survivors and/or zines.

Epistemic Injustice: theories and concepts

In the previous chapter I reviewed the literature which demonstrates the multiple ways in which survivors' knowledge about our own experience is marginalised. I also outlined how literature suggests that zines, the zine community and zine culture may have qualities which could benefit survivors reflecting on our experiences, articulating and sharing our understandings and having this appropriately valued. In this chapter I turn to consider theories about how knowledge, including survivor knowledge, is marginalised and how this might be addressed. I explore how these theories might help us understand, not only how survivor's experience epistemic injustice but also how we might use zines to work towards epistemic justice. In this way I outline my theoretical framework and the main concepts I will be using to understand survivors' use of zines. The theories I draw on have not yet been widely applied to the study of survivors' use of zines.

The limited literature about survivors' use of zines has been framed in terms of new approaches to pedagogy (Cameron 2012; Anderson and Spandler 2025) and community building (Eisenhauer 2010) but not on the need for greater epistemic justice that arguably underpins the need for both. Recent literature about the problems survivors face when it comes to reflecting on, articulating and sharing experiences and understandings, has been increasingly framed in terms of epistemic injustice. For example, Grim *et al.* (2019), Todd (2021), Crichton *et al.* (2017), Sanati and Kyratsous (2015), Wodziński and Moskalewicz (2023), Le Blanc and Kinsella (2016), Bueter (2021), Fisher (2023) and Scrutton (2017) all rely on Fricker's account of epistemic injustice. So, in the first section of this chapter, I outline Fricker's work on epistemic injustice and explain how the concepts *testimonial injustice* and *hermeneutic injustice* have been used in relation to survivors. Then, in the second section, I outline some criticisms of Fricker's work and describe how some of these can be addressed by using alternative concepts such as:

testimonial quieting, *epistemic oppression and epistemic violence* (Dotson), *structural testimonial injustice* (Anderson), *tone management/policing* (Bailey) and *testimonial smothering* (Dotson, Bailey and Medina). In the third section of this chapter, I consider theories that can prompt reflection on the multiple and complex environments in which epistemic (in)justice may be produced. For example, notions of *epistemic landscapes*, Dotson's notion of *contributory injustice* and Pohlhaus's account of *wilful ignorance*. I critically discuss how these concepts might be relevant to understanding survivors' use of zines and identify instances where they have been used in relation to survivors (e.g. Bueter, 2021; Le Blanc and Kinsella, 2016) or where they might be useful in understanding some survivors' experiences that I outlined in the previous chapter (Rose and Kalathil, 2019; Grim *et al.*, 2019; Laugharne *et al.*, 2012).

Fricker and epistemic injustices

Fricker (2007, p.1) describes epistemic injustices as “a wrong done to someone specifically in their capacity as a knower” and outlines two types of epistemic injustice which she calls testimonial injustice and hermeneutic injustice.

Testimonial injustice

Fricker writes that testimonial injustice “occurs when prejudice causes a hearer to give a deflated level of credibility to a speaker's word” (Fricker, 2007, p.1) and describes these as negative identity prejudices, which can ‘track the subject through different dimensions of social activity’ (p. 27). In contrast, Fricker (2007) describes testimonial justice as a virtue in which a hearer instinctually corrects for “familiar prejudices” and is alert to “the influence of less familiar prejudices” (p.98). So, for Fricker, testimonial injustice is connected to structural inequalities via identity prejudices, but she describes it as occurring as the result of actions of individual agents/potential hearers. This, in turn, means that testimonial injustice must be addressed through individuals changing how they listen and correcting any prejudices in order to evaluate the testimony shared with them.

Scruton (2017), Crichton *et al.* (2017), Sanati and Kyratsous (2015), Todd (2021), Bueter (2021), Fisher (2023) and Grim *et al.* (2019) have all used Fricker's (2007) account to theorise how survivors' testimony is often devalued. This included relating the concept of testimonial injustice to: survivors' accounts of being devalued as testifiers (Grim *et al.*, 2019); an NHS Trust not taking patient experience or feedback seriously (Fisher, 2023); mental health professionals assuming survivors perspectives are delusional (Sanati and Kyratsous, 2015); mental health tribunal panels failing to award authority to survivors who are subject to the Mental Health Act even if they have given testimony via an advance statement (Todd, 2021); and health professionals dismissing survivors' reports of physical symptoms (Bueter, 2021).

Hermeneutic injustice

Fricker describes Hermeneutic injustice as arising from being disadvantaged in making sense of experiences due to a gap in "collective interpretive resources" (Fricker, 2007, p.1). The hermeneutic resources Fricker draws attention to are conceptual. Fricker argues that, in sense making, we draw on a collective pool of conceptual resources and that because the pool is unduly influenced by hermeneutically powerful groups, and insufficiently influenced by the subject (i.e. the person relying on the pool to make sense of their experience), using this pool of conceptual resources can result in hermeneutic marginalisation. The professions Fricker (2007) describes as contributing to the pool of available hermeneutic conceptual resources are journalists, politicians and lawyers. So, Fricker (2007) describes hermeneutic injustice as a structural problem because gaps in the conceptual resources within the hermeneutic pool cannot be attributed to single agents. She argues that *virtuous hearers* might be able to mitigate instances of hermeneutic injustice, but to prevent it would involve "political action for social change" to shift "unequal relations of power that create the conditions for hermeneutic injustice" (2007, p.174).

Grim *et al.* (2019), Wodziński and Moskalewicz (2023) and Sanati and Kyratsous (2015) have used Fricker's idea of hermeneutic injustice to think about how survivors might be epistemically

disadvantaged. For example, Wodziński and Moskalewicz (2023) use Fricker's concept of hermeneutic injustice to explain how autistic people's interpretive practices are limited by hermeneutic resources which frame autism as a deficit or illness and suggest that, if psychiatrists rely on biomedical hermeneutic resources, they "may find it difficult to perceive and understand the psycho-social difficulties of patients" (Wodziński and Moskalewicz, 2023, p.8). Sanati and Kyratsous (2015) use the concept to write about how clinicians might lack the hermeneutic resources to make sense of psychotic experiences and delusions. Finally, Grim *et al.* (2019) use Fricker's concept of hermeneutic injustice to understand how some survivors feel restricted by being expected to use diagnostic frameworks to understand their experience, and to think about survivors not having access to the hermeneutic resources on which mental health professionals relied.

Alternative theories of epistemic injustice

Despite the benefits of Fricker's approach, it has been criticised for focusing on individual actions above social structures and institutions (Alcoff, 2010; Anderson, 2012) and for being a closed conceptual model (Dotson, 2012). Indeed, Fricker's definition of what constitutes epistemic injustice has been criticised for being so narrow that it might itself perpetuate epistemic oppression (Dotson, 2012). Dotson (2012) explains that epistemic oppression may be perpetrated because some patterns of silencing and exclusions from knowledge production are not included in Fricker's definition. For example, Fricker explicitly excludes silencing that is in line with common practices at a particular time and place, or based on interpretive resources being unrecognised by audiences. I suggest that this is highly relevant to survivors.

For example, Fricker (2007) makes a distinction between what she describes as innocent errors and testimonial injustice. She argues that for testimonial injustice to occur the person who devalues the testimony must morally wrong *in the context of the time and place in which the testimony is shared*. Therefore, because we live in a time and a place where survivors are widely perceived as having low credibility and epistemic authority, because of their mental health

status, according to Fricker's account, devaluing their testimony is not unethical and may just be an innocent error. If so, testimonial injustice would not be judged to have occurred in this instance. In other words, where the devaluing of survivors' testimony is rooted in the culture of the mental health system (and wider society) this devaluing is not, by Fricker's definition, testimonial injustice. Dotson (2012) criticises Fricker's notion of "innocent error", and her alternative concepts of testimonial quieting, epistemic oppression and epistemic violence may be more appropriate for describing the epistemic injustices survivors experience.



Image 2.1 "innocent error" but epistemic oppression/violence

It has also been suggested that, because Fricker's (2007) concept of hermeneutic injustice is developed from "one aspect of one distinct kind of hermeneutical marginalization" (i.e. marginalisation that arises from gaps in the conceptual resources created by people in positions of power), it may itself "contain a hermeneutical injustice" (Pohlhaus, 2012, p.724). Fricker has been criticised for not recognising that there are multiple epistemic environments and pools of resources (Dotson, 2012; Pohlhaus, 2012) and for not recognising that sometimes hermeneutic resources do exist but are not valued (Dotson, 2012; Pohlhaus, 2012). An example of this might be survivors' using the concept of sanism as an interpretive resource to make sense of our experiences, but finding that if we use it in the MH system our sensemaking isn't recognised or valued because the concept of sanism isn't valued in the MH system.

In addition, I suggest that Fricker's (2007) account of epistemic injustice does not address all the issues related to low epistemic confidence that I outlined in the previous chapter. I noted that the loss of epistemic confidence makes it difficult for survivors to reflect on and articulate their experiences (Scrutton, 2017; Hassall, 2022; Björk Brämberg *et al.*, 2018) and that survivors' loss of epistemic confidence may be difficult to avoid if the conceptual resources with which we are expected to rely on frame us as, by definition, lacking capacity to reflect on and articulate our experiences. With this in mind, epistemic confidence might itself be a hermeneutic (or interpretive) resource, and lack of confidence might be understood as potentially caused by gaps in conceptual resources, as well as by experiences of testimonial injustice. In other words, the focus on mental illness in the MH system makes it difficult for survivors and professionals to recognise survivors' epistemic capacities, which negatively impacts on survivors' epistemic confidence. In addition, survivors' epistemic confidence may be lowered through being expected to use conceptual resources that don't work for us, or to use words and linear structures when they don't fit with how we think or experience. This, in turn, results in difficulties articulating and then sharing our experiences.

The subsections below outline how alternative concepts might address these criticisms of Fricker and therefore aid understanding of survivor experience, zines and epistemology. First, I explore Dotson's (2011, 2012, 2014) ideas about responsibility, and the distinction between individual culpability versus ongoing patterns of disadvantage or harm. Next, I consider Anderson's (2012), distinction between structural and transactional theories of justice. Third, I outline Bailey's (2018) contribution about the tone management and silencing of angry testimonies. Then I return to Dotson to propose the relevance of the concept of *testimonial smothering*.

Testimonial quieting and epistemic oppression and violence

Instead of focusing on whether the potential listener may, or may not, be culpable or unethical for the time and place (as Fricker does), Dotson (2011) argues for a focus on 1) whether

difficulties articulating experiences and sharing knowledge are part of a pattern, and 2) whether harm is caused. Dotson provides three terms to help understand these dynamics – *testimonial quieting*, *epistemic oppression* and *epistemic violence*.

Testimonial quieting is used to describe instances where “an audience fails to identify a speaker as a knower” (Dotson, 2011, p.242). If testimonial quieting is part of a pattern of silencing, Dotson refers to it as epistemic oppression or epistemic violence. For people to be able to contribute to the production of knowledge, Dotson (2011) notes that epistemic resources must be useable, and their audience must perceive them as a knower. If these circumstances don’t happen, and there is a “persistent and unwarranted infringement on the ability to utilise shared epistemic resources [which] hinder one’s contributions to knowledge production”, Dotson calls this *epistemic oppression* (2014 p.116). Whereas a refusal to hear testimony that is caused by ignorance and is consistent with, or follows from, a predictable epistemic gap in resources, and harm is caused, Dotson (2011) calls this *epistemic violence*. So, in contrast to Fricker, Dotson’s (2011) approach gives an account of *epistemic oppression* and *epistemic violence*, regardless of whether the person who devalues the testimony is deemed culpable or not. and regardless of whether or not they are framed as uncredible knowers in wider society. As should be clear, this amendment is highly relevant to understanding survivor’s predicament...



Image 2.2 Epistemic oppression and epistemic violence

Dotson (2011) notes that understanding harm arising from ignorance “requires an analysis of power relations and other contextual factors that make the ignorance identified in that particular circumstance or set of circumstances harmful” (Dotson, 2011, p.239). This is important because the power differentials in the MH system mean that when MH professionals devalue survivors’ testimony, survivors are much more likely to be harmed than they would be if a stranger devalued their testimony. For example, I might not be harmed by a stranger devaluing my account, whereas in services the person devaluing my account is in the position to decide my treatment or support and may result in me being given (or refused) treatment (or support) that is damaging. There isn’t a lot of literature which refers to survivors’ experiences in services as epistemic violence. However, relating their experiences of being silenced in MH services to their psychiatric confinement, survivor activist Daya (2022) has described the silencing of their personal truth as “the most insidious and damaging kind of confinement” (p.5). In terms of healthcare more widely, referring to Kidd and Carel (2018), Barker *et al.* (2018) note that when the testimony of ill people regarding their treatment, isn’t taken seriously by healthcare it can “lead to serious harms” (p.15). Kidd and Carel (2018) describe epistemic harms in healthcare as manifesting “in miscommunications between patients and health professionals, complaints by patients of their concerns and interests being ignored, overlooked, or dismissed, in rhetorics of ‘silencing’, and continued feelings of dissatisfaction, as well as, in some cases, flawed clinical care” (p.211). They further note that the “epistemic harms and wrongs suffered by ill persons in healthcare settings...[negatively] impact upon patients’ clinical care, psychological and physical health, social confidence, and lived experience” (p.211).

Concepts like *testimonial quieting* create space to understand the ways in which the problems survivors experience may be attributed to a culture or epistemic system as opposed to (or in addition to) the actions of individual potential listeners. They create space for us to explore how different cultures and epistemic systems might be utilised to address the ways in which survivors are epistemically excluded. In addition, Dotson’s distinction between *epistemic*

oppression and *epistemic violence* enables us to attend to the significance of context and in particular the power dynamics in which testimony is shared. This, in turn, may be useful for exploring how sharing testimony in different contexts or power relationships might alter survivors' experiences.

Structural testimonial injustice

Anderson (2012), like Dotson, critiques and expands on Fricker's definition of epistemic injustice. Anderson (2012) takes issue with Fricker's emphasis on individuals rather than social institutions and introduces a distinction between *transactional* theories of justice (like Fricker's) that provide criteria for fair personal interactions, and *structural* theories that provide criteria for a fairer system which govern interactions. Anderson (2012) argues that because Fricker's account is transactional it doesn't include, and cannot account for, structural testimonial injustices that do not arise from prejudiced hearers, but where members of disadvantaged social groups still suffer from unfairly decreased credibility. Anderson (2012) argues that *structural testimonial injustice* takes place "when institutions are set up to exclude people without anyone having to decide to do so" (Anderson, 2012, p.166). Although some researchers have applied Anderson's idea of structural testimonial injustice to survivors (e.g. Bueter, 2021), it hasn't been widely applied to this population, despite (as I outlined in my previous chapter) power dynamics in the MH system meaning that survivors are often dependent on being invited to contribute. Anderson's idea of structural testimonial injustice may be useful for thinking about whether the zine community might epistemically advantage (or disadvantage) survivors. It may also be useful for contrasting survivors' experiences of the structure of zine community with their experiences of the structure of the MH system.



Image 2.3 Structural testimonial injustice

Tone management/policing of anger

Expanding Fricker's notion of what constitutes testimonial injustice, Bailey (2018) has argued that marginalised people are epistemically disadvantaged by the silencing of anger and the devaluing of angry testimony/angry testifiers. Bailey (2018) suggests that marginalised people tend to be stereotyped as angry and because knowledge of injustice (including epistemic injustice) is often entwined with and contained within anger. She argues that pathologizing and silencing anger robs it of its epistemic content, and this effectively silences people's ability to communicate injustices (Bailey, 2018). In other words, injustice makes people angry and, if we silence this anger, we make it difficult to communicate the injustice because the anger and the injustice are difficult to separate from one another.

Bailey (2018) argues a spiral can be created in which silencing leads to anger, then anger is silenced and with it the knowledge of the injustice of being silenced, which leads to further anger, and so on. Bailey's (2018) ideas may be particularly pertinent to understanding survivors' experiences of being silenced because survivors may be particularly vulnerable to being stereotyped as overly or inappropriately angry. When survivors are given a psychiatric

diagnosis, the emotions we feel are often decontextualised and perceived in terms of our pathology and not as evidence of injustice.

Some literature has linked zines with sharing anger (Licona, 2012; Cofield, 2018; Hwang, 2022) which suggests there might be epistemic advantages to survivors sharing angry knowledge and, by association, knowledge of injustices via zines. Therefore, Bailey's ideas may also be relevant to understanding what zines might offer survivors.

Testimonial smothering

Dotson (2011) writes about a type of testimonial silencing that doesn't fit in Fricker's account of epistemic injustice, which she calls *testimonial smothering*. This concept is useful because Fricker's (2007) account of testimonial injustice does not account for the ways in which potential testifiers might evaluate their potential audiences. Dotson (2011) describes potential testifiers as assessing whether they think the audience will be willing and able to receive and value testimony and then changing their testimony accordingly. Dotson notes that potential testifiers need the intended audience to perceive us as capable epistemic agents, and we also need the receiver to recognise, understand and value the way(s) in which we share our knowledge. She argues that when potential testifiers perceive their audience to be unwilling or unable to receive and value their testimony, they truncate their testimony. She calls this process *testimonial smothering*.

Dotson (2011) writes that testimony is smothered when it is risky or unsafe to share; in other words, testimony is smothered when individual testifiers, or a group they are members of, might be harmed if they share the testimony. She links this to testifiers evaluating an audience's capacity and willingness to receive their testimony. Dotson (2011) describes risky or unsafe testimony as "testimony that an audience can easily fail to find fully intelligible" which, she suggests, "runs the risk of leading to the formation of false beliefs that can cause social, political, and/or material harm." (p.244). In a similar vein, Medina (2012) notes that "sometimes

oppressed or marginalised publics do not communicate with other publics [because] ... it is not in their best interest to do so" (Medina, 2012, p.101). Bailey (2018) further argues that smothering can include what she refers to as *affect smothering*, i.e. the smothering of anger and the knowledge entwined with it.



Image 2.4 Testimonial smothering

Dotson (2011) argues that, although *testimonial smothering* involves some kind of capitulation or self-silencing on the part of the potential knowledge sharer, it is a type of coerced silencing. Put another way, people often feel like they have no choice but to smother their testimony. As I outlined in my previous chapter, there is some evidence that at times survivors don't feel able to share knowledge in the MH system because of the vulnerability of their position in relation to MH professionals (Rose and Kalathil, 2019; Grim *et al.* 2019; Laugharne *et al.*, 2012). Although these researchers don't refer to Dotson's concept of *testimonial smothering*, it may be usefully applied to survivors' experiences of the MH system. The concept of *testimonial smothering* may also be useful to explore in which contexts survivors feel we have to smother our testimony and in which contexts we don't. It may be another way of understanding the contrast between the culture of the MH system and the zine community. The idea of testimonial smothering may help us think about if/how survivors evaluate audiences in the zine community vs audiences in the MH system and the significance of this in relation to epistemic (in)justice.

Understanding multiple epistemic environments

Fricker's (2007) account of hermeneutic injustice has been criticised for not recognising that there are multiple epistemic environments; for assuming that there is one pool of hermeneutic resources on which we all rely (Dotson, 2012; Pohlhaus, 2012); for not taking full account of the contexts in which marginalised people can and do create and use interpretive resources that work for them (Pohlhaus, 2012); and for not taking full account of how social situatedness affects how people make sense of the world (Pohlhaus, 2012; Alcoff, 2010). Fricker has also been criticised for not taking full account of power relations or "the role power plays in hindering the hermeneutical resources of the marginalized" (Dotson, 2012, p.31).

So, in this section of this chapter, I outline accounts of epistemic injustice which are based on the recognition of the complexity of the social world and the multiplicity of epistemic environments (Pohlhaus, 2012).

Epistemic landscapes

Whilst Fricker (2007) focused on a single set of hermeneutic resources in her account of epistemic injustice, many other theorists have referred to the existence of multiple epistemic worlds, multiple pools of hermeneutic/epistemic resources, different epistemic systems and different fields of production. For example, Medina (2012) has argued that to understand "social silences and the epistemic harms they generate" analysis must take into account "different interpretive communities and interpretive practices" (p.90). Similarly, Dotson (2012) refers to "hermeneutically marginalized communities" as having their own "epistemologies, counter-mythologies and hidden transcripts" (p.31) and argues that there is always more than one set of hermeneutic resources available, that people don't always recognise this because of situated ignorance. Further, Bailey (2018) has referred to women who have experienced sexual violence seeking out or creating "worlds" where their anger about these experiences is "intelligible" (p.106).

This idea is likely to be important for understanding survivors' experiences of zines and epistemic (in)justice because it makes it possible to explore how epistemic experiences in the zine community might differ from those in the MH system. For example, the idea of multiple epistemic worlds/environments makes it possible to explore what can happen if survivors' step outside the MH system to reflect on and articulate our experiences. It also makes it possible to explore what the zine community has to offer as an epistemic environment, why people might opt into it as an epistemic environment and whether the zine community is an epistemic environment that has been created by and for people who want to find their experiences intelligible but have not found this the case in other environments.

Dotson (2014) has described epistemic landscapes as being comprised of schemata, application and practice, and *epistemological systems*. She relates schemata to the tools and resources that are available and the ways in which these are structurally perpetuated. She also writes about the ways in which schemata are (or aren't) reenforced in practice. This might include in practice what knowledge is/can be shared, with whom, by whom, and in what context, and what knowledge is used/acted upon. She relates epistemological systems to the types of interpretive tools and resources used: in other words, how we (can) know what we know. Dotson (2014) writes that epistemic systems include "operative, instituted social imaginaries, habits of cognition, attitudes towards knowers and/or any relevant sensibilities that encourage or hinder the production of knowledge" (p.121).

If we think of the mental health system as an epistemological landscape, the practice would relate to whether we can share our knowledge and whether our knowledge is valued and acted on. In this way the practice relates to testimonial quieting, structural testimonial injustice and testimonial smothering. The schemata would relate to which concepts were available e.g. which diagnoses or which concepts for understanding and treating diagnoses are available, in this way it relates to hermeneutic injustice. The epistemological system is more fundamental, it

is about the system of resources used and the way that resources are interlinked. This might include, for example, whether there is a system of diagnosis, or a system of relying on positivism. Epistemological systems might include ideas about what is considered reality and how we believe we can know it. Epistemological systems might also include expectations of how communication should be structured, ideas about whether experiences can be understood or communicated via image or metaphor, how sensitive or responsive we are to different forms of knowledge or articulation, and how we perceive and evaluate knowers. The important thing about epistemological systems is the way in which they are comprised of interlinked resources/tools/ways of thinking and perceiving. Dotson (2014) argues that the ways in which resources/tools are interlinked makes epistemic systems resilient and very difficult to change.

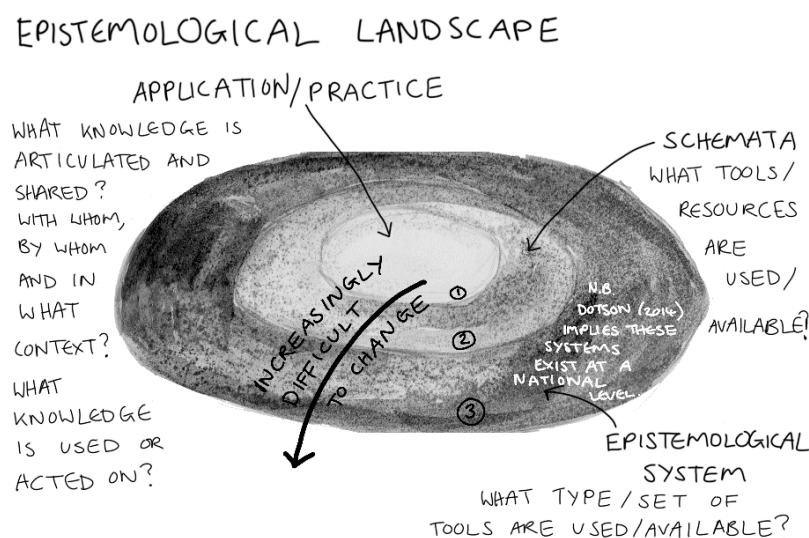


Image 2.5 Dotson's epistemological landscape

Dotson's (2014) account of epistemic landscapes is relevant to survivors because, as I outlined in the previous chapter, survivors in the MH system are disadvantaged by the MH system's focus on positivist epistemology as well as by survivor created concepts and knowledge not being valued in the MH system. Survivors might even be described as being disadvantaged at every level in the epistemic landscape of the MH system. It is relevant to the study of zines because it can help us explore how different aspects of the zine community might advantage/disadvantage

survivors. Dotson's account of epistemic landscapes may also be useful for understanding how and why survivors might move between different epistemic landscapes.

Contributory injustice and wilful ignorance

Dotson (2010, 2012) and Pohlhaus (2012) have also developed theories of epistemic injustice which are based on the recognition of multiple epistemic landscapes. Like Pohlhaus (2012), Dotson (2012) notes that marginalized groups have (or develop) concepts and understandings to make sense of their experiences, but these interpretive resources aren't widely adopted, and are wilfully ignored by dominantly situated knowers. In other words, audiences in positions of power may be relying on epistemic systems, stereotypes and hermeneutic resources which might be seen as reliable and well-used in a particular time and place, but are not suited to the context in question, for example understanding the experiences of marginalised people. Therefore, whilst marginalised people might be able to make sense of their experiences, the dominantly situated people are not able to receive this understanding.



Image 2.6 Contributory injustice/wilful ignorance

Pohlhaus (2012) suggests that, whilst marginalised people are familiar with their own experience and the resources which they use to make sense of this, they are also aware of the dominant interpretive resources because they have to be. However, she suggests that dominantly situated people might not see the need for the interpretive resources marginalised

people develop and use, or might not be motivated to recognise them: “When a group with material power is vested in ignoring certain parts of the world, they can ... maintain their ignorance by refusing to recognize and by actively undermining any newly generated epistemic resource that attends to those parts of the world that they are vested in ignoring.” (Pohlhaus, 2012, p.728). She calls refusing to learn to use epistemic resources developed from marginalized situatedness “*willful hermeneutical ignorance*”(ibid p.722) and suggests it is a type of what Dotson (2010) called *contributory injustice*. Pohlhaus (2012) gives the example of dominantly situated people dismissing “the viability of such arduously honed concepts like “white privilege,” “date rape,” or “heteronormativity” (p.722).

As I outlined in the previous chapter, some survivor-generated conceptual resources like sanism, the unrecovery star and the language of madness are not widely adopted by MH professionals in the MH system (Le Blanc and Kinsella, 2016). In other words, you could argue that MH professionals might be engaging in what Pohlhaus (2012) calls wilful hermeneutic ignorance and what Dotson (2010, 2012) calls contributory injustice.

Whilst Fricker (2007) argues that an audience’s use of stereotypes might be described as an innocent error resulting in the testifier experiencing epistemic bad luck. However, Dotson (2012) argues that they may be using ill-fitting hermeneutical resources and this amounts to contributory injustice, that is “caused by an epistemic agent’s situated ignorance, ... maintaining and utilizing structurally prejudiced hermeneutical resources that result in epistemic harm to the epistemic agency of a knower” (p.31). Even if there is some truth to the stereotypes about survivors’ capacity to know things/ non-linear testimony, they are not appropriately applied in all situations. For example, even if a survivor received a diagnosis which indicated that they were lacking in insight and professionals thought this was a reliable stereotype in relation to people who receive that diagnosis it might not be reliable outside of that context, for example when the survivor is reporting physical symptoms or providing critiques of services. Using this diagnosis/stereotype in contexts when there are other

interpretive resources available would, by Dotson's (2012) account, be considered contributory injustice because the audience is using hermeneutic resources that are not appropriate for the task in hand, resulting in epistemic harm. Similarly, even if stereotypes about non-linear testimony being non-sense were true in some cases, it may not be appropriate to apply these stereotypes in all contexts. If this stereotype is applied to survivors' accounts of trauma, for example, listeners might be described as using prejudiced hermeneutical resources which result in epistemic harm to the knower, because non-linear forms might be necessary to articulate, understand and share these experiences.

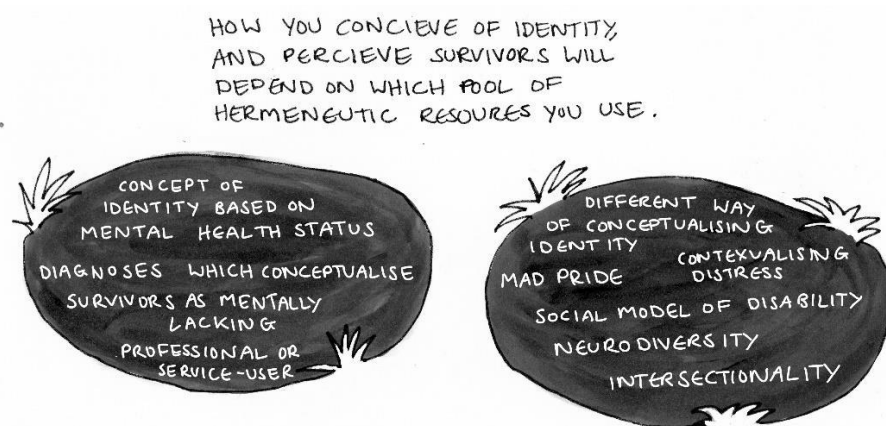


Image 2.7 Identity and hermeneutic resources

The idea that testifiers and audiences can choose to use different epistemic resources or systems is significant as it calls attention to the question of who is judging whether the epistemic resources and systems being applied are appropriate to the context in which they are being used. It is also significant because contributory injustice may be a type of epistemic injustice that survivors are especially vulnerable to. For example, part of what results in survivors' testimony being devalued in the MH system may be the reliance on deficit models of madness/neurodivergence (Wodziński and Moskalewicz, 2023) and on an epistemic system which excludes subjective interpretations (Carel and Kidd, 2014; Florsheim, 2020; Rose and Kalathil, 2019). Indeed, Wodziński and Moskalewicz (2023) note how the medical model conceptualises survivors in terms of deficit which can make it difficult for us to see our

strengths. In a similar vein, when my testimony has in the past been devalued by MH professionals, I believe it was partially because they relied on diagnosis to understand my experiences of distress and to form their perceptions of me. For example, when I shared an account of an experience, a nurse in the MH system labelled me as lacking in insight but the same account was described by a reviewer as insightful when I shared it in a book. My sense was not that the nurse was necessarily prejudiced. My sense was that he wasn't able to recognise the way in which I had made sense of and articulated my experience, because I was drawing on a set of interpretive resources/epistemic system that he didn't recognise and he only saw me, my experiences and my account through the biomedical model and therefore wasn't able to recognise my epistemic capacity. In other words, the nurse limited himself to interpretive resources created by and for MH professionals which meant he missed my understanding, and I missed out on having my understanding recognised and valued. In contrast, the book reviewer had a very different response because he drew on a different set of interpretive resources.

Therefore, Dotson's (2012) account of contributory injustice and Pohlhaus's (2011) account of wilful ignorance are likely to be useful for understanding survivors' experiences because survivors have developed (and use) conceptual interpretive resources that haven't been widely recognised, used or valued in the MH system. It is also useful for understanding how the devaluation of survivors as testifiers in the MH system may be due in part to MH professionals relying on hermeneutic resources that are biased and inappropriate for the task in hand.

In addition, these accounts may be useful for helping us to think about the conditions in which it is possible for survivors to use the conceptual interpretive resources we develop and consider whether zines provide these conditions. They may also be useful for exploring whether people in the zine community rely on different hermeneutic resources or systems to those used in the MH

system and, if so, whether this changes how they perceive survivors and, in turn, changes how they evaluate survivors as knowers.

Summary

In summary, theories of epistemic injustice have been increasingly applied to survivors, specifically Fricker's account. However, theories of epistemic injustice have not yet been widely applied to the study of zines or survivors' use of zines. Moreover, Fricker's specific account isn't very helpful for understanding the ways in which the survivors of the MH system experience epistemic injustice. Therefore, this chapter has outlined some relevant alternative theories and concepts of epistemic injustice that I will use to understand survivors' use of zines.

I have suggested that these theoretical developments have potential to enable us to make sense of the multiple ways survivors are silenced and our knowledge is excluded from diverse settings and to understand the multiple ways survivors' experiences of epistemic injustice might be addressed. They also have potential to enable us to contrast survivors' experiences of the zine community with survivors' experiences of the MH system, and to understand the difficulties survivors might have in sharing knowledge between the zine community and other epistemic landscapes like the MH system. There is a lack of literature relating experiences of making and sharing zines to theories of epistemic injustice or theories about social structures and the production and valuing of knowledge. Therefore, the rest of this thesis will apply these theories to help us understand how and why survivors might use zines to work towards epistemic justice.

Zine-centred survivor-friendly methodology

Introduction

In this chapter I outline my survivor-friendly zine-centred methodology. My methodology is survivor-friendly because I use a methodology and set of methods which attempt to value and honour survivors' perspectives and the ways in which survivors think and articulate ourselves. It is zine-centred as I used zine-making as a form of reflective analysis throughout my research. I begin by introducing my methodological approach which draws on (Critical) Participatory Action Research (C)PAR, Narrative Research, Autoethnography and Arts-Based Research, which centres drawing and zine-making as analysis. I then describe the methods I used and the various stages, processes and analysis I employed during the research.

Methodological approach

As a whole, my approach can be described as bricolage. Bricolage involves using a combination of methods and drawing on a variety methodological and interpretive perspectives. Bricolage has been described as offering researchers “a dynamic toolkit to navigate the complexities of social phenomena” (Santiago Sanchez *et al.*, 2024, p.1). In bricolage, research design is based on the context of the focus of the study, an appreciation of different epistemological and ontological assumptions and conventions, and an understanding of different methods of inquiry (Kincheloe, 2001). In other words, it involves the researcher holding these in mind whilst deciding which are most appropriate to the task in hand.

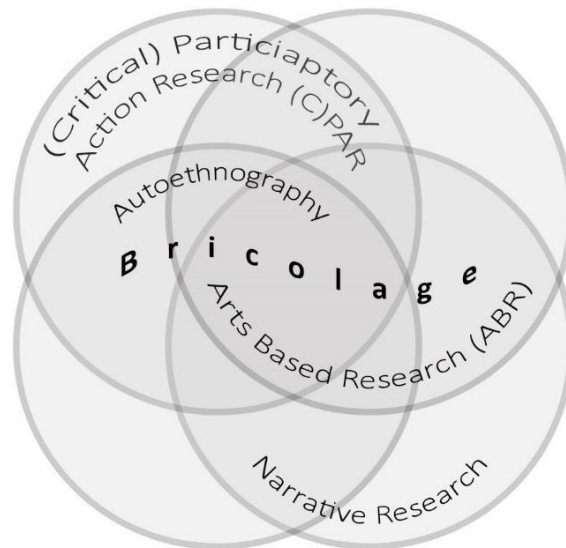


Image 3.1

My approach (represented in the image above) draws on (Critical) Participatory Action Research ((C)PAR), autoethnography, Arts-Based Research (ABR) and narrative research. I give a brief outline of each and how and why I draw on them below.

(Critical) Participatory Action Research

Participatory Action Research (PAR) is an iterative process which involves multiple cycles of planning, action and reflection (Marshall and Rossman, 2006; Selegner, 1997). PAR involves a commitment to the active involvement of participants in the research process (Grbich, 1999; Minkler and Wallerstein 2003) which “recognizes the need for persons being studied to participate in the design and conduct of all phases ... of any research that affects them” (Vollman *et al.*, 2004, p.129).

PAR further involves questioning the nature of knowledge and to what extent knowledge represents the interests of the powerful and serves to reinforce their positions in society. For example, it acknowledges that we can know things through experiencing them and that experiential learning can lead to a legitimate form of knowledge that influences practice (Kolb, 1984).

PAR aims to be emancipatory and benefit participants by fostering empowerment and social justice (Vollman *et al.*, 2004) and creating personal and social changes (Kemmis, 2008). Indeed, PAR has been described as a liberating and life-enhancing process (Koch *et al.*, 2002). Critical participatory action research (CPAR) focuses more explicitly on questions of power and injustice, intersectionality and action (Fine and Torre, 2021). It involves using participatory methods and practice for intersectional knowledge production (Fine *et al.*, 2021). CPAR is 'critical' in that it focuses on participants discovering how particular perspectives, social structures and practices 'conspire' to produce adverse effects, with the aim of finding ways to create change so these adverse effects can be avoided (Kemmis, 2008).

My approach draws on (C)PAR in that it is based on a commitment to valuing marginalised knowledge and experience, using participatory (Grbich, 1999; Minkler and Wallerstein, 2003) and emancipatory methods where possible (Vollman *et al.*, 2004; Koch *et al.*, 2002; Kemmis, 2008). It also uses multiple iterations of reflections and analysis, with each stage contributing to how next stage of the research is carried out (Marshall and Rossman, 2006; Selener, 1997).

I draw on (C)PAR because it is important I make a commitment to valuing marginalised knowledge and experience and resisting existing structure of power, given that this research seeks to understand how survivors might use zines to tackle epistemic injustice. In other words, my research is fundamentally about the valuing of marginalised (survivor) knowledge. My commitment to participation is also intended to echo the culture of participation scholars have described in the zine community (Duncombe, 2017; Piepmeier, 2008, 2009; Watson and Bennet, 2020; Cameron, 2012; Triggs, 2010) and I use participatory methods to demonstrate that I value the participatory nature of zine culture. Indeed, the wider MadZines project, of which this study was a part, sought to find an approach which was emancipatory and "congruent, with the ethics and culture of both zines and mad studies" (Spandler and Anderson, 2021).

I drew on the way that PAR recognises the value of experiential knowledge (Kolb, 1984), because it has been argued that survivors would benefit from experiential and subjective knowledge being valued (Crichton *et al.*, 2017; Scrutton, 2017) and because one of the things I explore is what can be learned through the experiences of creating, sharing and reading zines. To understand how survivors might use zines to articulate and share knowledge, I must first recognise that creating, sharing and reading zines are processes through which knowledge might be articulated and shared. In other words, drawing on the way in which PAR recognises and values experiential and subjective knowledge is important because doing so enables the research to centre on/explore survivors' accounts and experiences and makes it possible to explore what zines might have to offer.

Autoethnography

In autoethnography "the researcher is a complete member in the social world under study" (Anderson, 2006, p.379). Auto ethnographers themselves "form part of the representational processes in which they are engaging and are part of the story they are telling" (Atkinson *et al.*, 2003, p.62). Autoethnography is a process through which a researcher connects their personal experience to wider social understanding (Adams *et al.*, 2021; Anderson, 2006; Ellis *et al.*, 2011). I draw on autoethnography in that I treat myself as a participant as survivor zine maker and draw on my own experiences and reflections as part of my analysis throughout this thesis.

I draw on autoethnography because my own experience is readily available data which is relevant to my research. Autoethnography enables researchers to "illustrate analytic insights through recounting [their] own experiences and thoughts as well as those of others" (Anderson, 2006, p. 384). Given that I am a member of the social world that I am studying, I was conscious I would inevitably draw on my experience and using autoethnography was a way to acknowledge this and make it explicit. Drawing on autoethnography was also a way to honour the ways in which many people, including myself and my participants, reflect on their own experiences in perzines (Liming, 2010).

Drawing on autoethnography has helped me think about my “dual participant-observer role” (Merton, 1988, p.18) and the ways in which I am both a member of the group I’m studying and a member of a research community (Strathern, 1987). It has helped me consider the reciprocal influence between me, the research context and my participants. Drawing on autoethnography helped me to think about how reflecting on my own experiences as well as those of my participants might enable me to “develop and refine generalized theoretical understandings of social processes” (Anderson, 2006, p.385) – in my case, the processes of survivors making and sharing zines...

Arts-based research

Arts-based research (ABR) is generally the use of artistic activity within the research process, whether carried out by researchers or participants. McNiff (2008) writes that ABR can be defined as “the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies” (p.29).

ABR can include: using artistic activities to gather or create data (Ward and Shortt, 2012; Leigh *et al.*, 2024); using creative processes to analyse and interpret information (Barratt, 2024; Gascoine *et al.*, 2024; Thomas, 2024); and sharing findings through creative mediums (Thomas, 2024; Hodges, 2024). Indeed Leavy (2015) argues that ABR can be beneficial to each of these stages. ABR has been described as helping build and strengthen relationships between researchers and participants (Hodges, 2024); and making the process of analysis accessible and engaging for participants in the process of analysis (Barratt, 2024; Duncan, 2024). ABR can enable participants and researchers to capture intangible experiences that would be difficult to verbalise (Barratt, 2024). It has also been seen as a method that may be particularly accessible and useful for neurodivergent researchers (Grant and Kara, 2021; Roberts and Collis 2024). Visual representation of data has been seen as a tool to help compare different sets of data (Gascoine *et al.*, 2024), mapping data visually can help researchers reflect on relationships,

commonalities and differences (Neilson and Kenny, 2024), whilst drawing can help reflection on emotional experiences (Barratt, 2024).

My methodology was arts-based in that I used a visual process to identify themes and connections, and code and interpret my data. Specifically, I used drawing and zine-making to do this. My methodology was also arts-based in that some of the data collected was in the creative form of zines. Finally, I include images I drew throughout this thesis to communicate my ideas.

To ensure my research method reflects my research subject, I use zine-making techniques and practices as part of my process of analysis and zines as a way to communicate my research.

Through using zines and zine-making as method, I hoped to explore and to demonstrate the potential of zines to generate and communicate new knowledge. I have found one other example of zine-making being used as analysis (Biagioli *et al.*, 2021).

By generating and sharing knowledge in zine form I demonstrably reject the idea that knowledge must be in an academic article or book to be of value. I also demonstrate that I value zines as a way to generate and communicate knowledge. This is important if making and sharing zines is a survivor's chosen means of communication, and method of gathering and organising information. Centring survivors' experiences without re-enacting epistemic injustice means centring survivors' meaning-making processes as well as survivors' complex experiences.

The creative processes I use also suits how I think, and I hope that including images will help make my thesis more engaging and accessible as a research output.

Narrative research

One of the defining features of narrative research is that it honours individual narratives, as narratives, rather than merging them or picking out themes (Reissman, 2008). This is important in regard to survivor's accounts, which have often been taken out of context and disconnected from their individual experiences and the intersectionality of these, which can contribute to

experiences of epistemic injustice. I draw on narrative research because I am committed to understanding the complexity of individuals' experiences as a whole (Reissman, 2008).

Drawing on a narrative approach also enables me to explore a range of different, and sometimes conflicting, experiences. Individuals don't fit neatly into easily defined categories, whether these are diagnostic categories, or categories used to describe social variables like race, ethnicity or class. By categorising people, we can make generalisations, but we also lose individual information, smoothing out the details. As one of my participants said, one of the things that is most precious about zines is that they don't have to be about a generalisable experience in the way that books might be expected to be; they can be, and often are, about one person's very specific experience.

Qualitative methods and interpretivism

All the methodologies that I draw on are qualitative. Qualitative methodologies aim to describe and understand (Streubert and Carpenter, 2011), they focus on human experience and the meanings ascribed by individuals living the experience (Mason, 2006; Greenhalgh and Taylor, 1997) and seek to interpret and document phenomena from the viewpoint or frame of reference of the participants/people being studied (Creswell, 1997; Mason, 2006; Gilbert 2001). They are therefore appropriate for this study which seeks to describe survivors' experiences of creating, sharing and reading zines and to understand how, why and to what effect they might use zines to address epistemic injustice.

My epistemology is interpretivist, in contrast with the positivist epistemology which has been described as epistemically disadvantaging survivors in the mental health (MH) system (Rose and Kalathil, 2019; Crichton *et al.*, 2017; Scrutton, 2017). Interpretivism is interested in subjective experience. Interpretivism involves a recognition that there is "no single, objective reality" but instead "there are multiple realities based on subjective experience and circumstance" (Wuest, 1995, p.30). We can only understand someone's reality through their

own experience of that reality, which may be different from another person's and will be shaped (amongst other things) by their historical and social context. Recognising this is fundamental to this research as it seeks to understand the different subjective experiences of my participants.

Process and methods

This section outlines the different steps I took, how I defined and justified my sources and methods of data collection and what methods I used in my analysis. This section will include some reflections about the process of gaining ethical approval.

My research took part in two main stages. In the first stage I reflected on my own experiences of creating and sharing zines and zine-like texts, applied for university ethics approval, interviewed survivor zinesters about their experiences of creating and sharing zines, and then reflected on this and developed plans for stage two. In the second stage I introduced multiply marginalised survivors to zine-making, I interviewed them, conducted zine-making sessions with them and set up an opportunity for them to share their zines with each other.

Stage one

The data collected for the first stage included interview transcripts, participants' zines that were publicly available, and that they spoke about during the interviews, and participants' zines that they chose to share with me before, during and after the interview. However, I started with my own reflections about being a survivor zine-maker.

My reflections

Drawing on standpoint theory (Harding, 1993), I take the view that as a survivor I am likely to have insights and understandings that non-survivors don't have (Burstow, 2015). Indeed Ritunnano (2022) has argued that better representation of survivors in mental health research may itself help address epistemic injustice. Moreover, Faulkner (2010) concluded that the survivor researchers tended to examine themes and issues of concern to marginalised communities that would not have been identified or researched by people who are not MH

system survivors. Being a survivor myself also meant I shared this experience with my participants which I hoped would help relationship building. This is important because survivor knowledge tends to be devalued in most research settings (Rose and Kalathil, 2019) and research has been described as a site of epistemic injustice (Quantz *et al.*, 2019; Frank, J., 2013).

My reflections included the following. I reflected upon my survivor identity and my position as a researcher and how they intersect. This included reflecting on my own experiences of participating in research as a survivor. I also reflected on my relationship with the zine community and my experiences of creating and sharing zines, including how qualities of zines and the zine community had helped or hindered my own ability to create and share my ideas and experiences. Some of my initial reflections can be found on the MadZines website (Walker, 2021; Walker and Anderson, 2021).

Reflecting on all this helped me to think about how not to perpetuate epistemic injustice during the research. Researchers tend not to come from marginalised communities, or those most impacted by policy and practice, meaning researcher biases can remain unchecked and academics as a dominant group can keep “the experiences of disenfranchised peoples in the margins or out of discourse altogether” (Quantz *et al.*, 2019, p.121). As an able-bodied white researcher with higher education, I am privileged in ways that some of my participants aren’t and people in privileged positions often struggle to understand the experiences and perspectives of people who don’t share their position. Through reflecting on my position, perspective and biases I was able to think about how I might best understand my participants positions/perspectives and identify ways for these to be included and given a platform.

Not surprisingly, given the nature of the research and my own background as a survivor zine maker, I used zine-making as part of my process of reflection, and I continued to use zine-

making to reflect on ideas that came up during the research and to reflect on my own process.¹⁵ This involved capturing and reflecting on my experiences using creative and visual methods. Like Brown (2024), I found that through engaging in creative techniques I was able to “make sense and learn through doing” (p.108). Making and sharing zines, as well as reading them, has also been fundamental to the wider MadZines project. Indeed, “zine making has helped us to engage with ideas that we’ve encountered in books and journal articles [and] helped us to process learning from events that we have organized or attended” (Anderson, 2025). The following pictures from my zines illustrate how I used this process to understand certain ideas and concepts (see image 3.2, 3.3, 3.4 and 3.5)

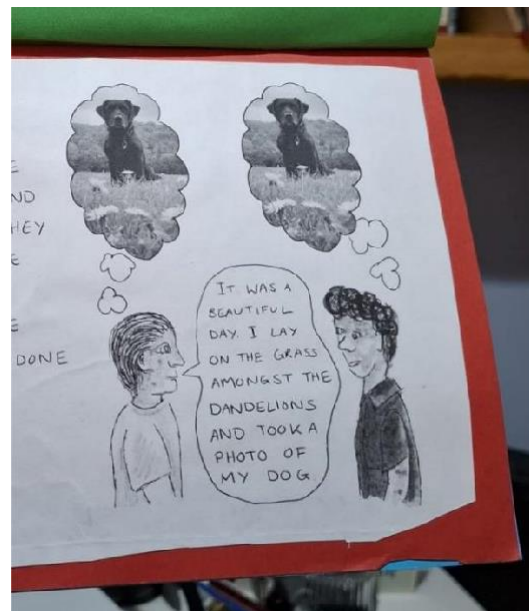


Image 3.2 reflection on reciprocity in communication from a zine reflecting on my reading of theories of epistemic injustice

¹⁵ Some of my reflective zines can be found in the Wellcome Library zine collection (for example: The problem of knowledge; Understanding people’s real lives and Personal Process: Nobody will teach you (r)evolution).

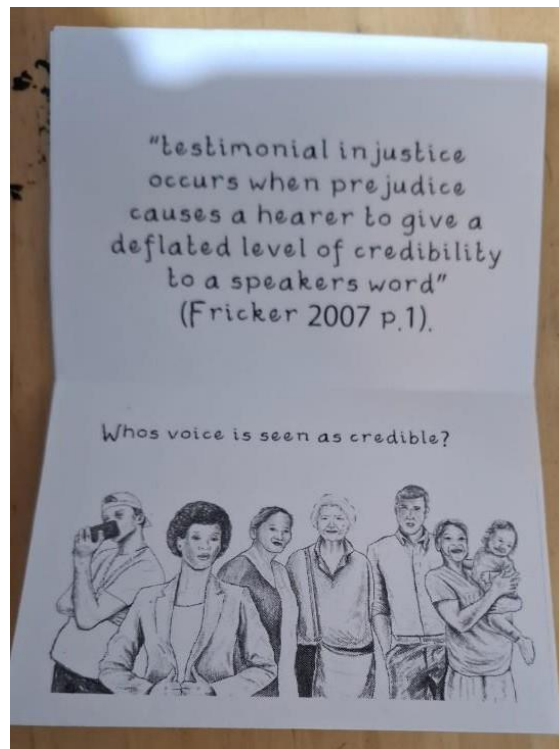


Image 3.3 reflection on Fricker's 2007 account of testimonial injustice from a zine relating epistemic injustice to survivors and zines

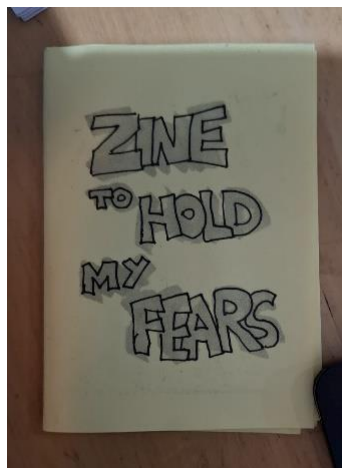


Image 3.4 zine I created to explore how zines might work as containers

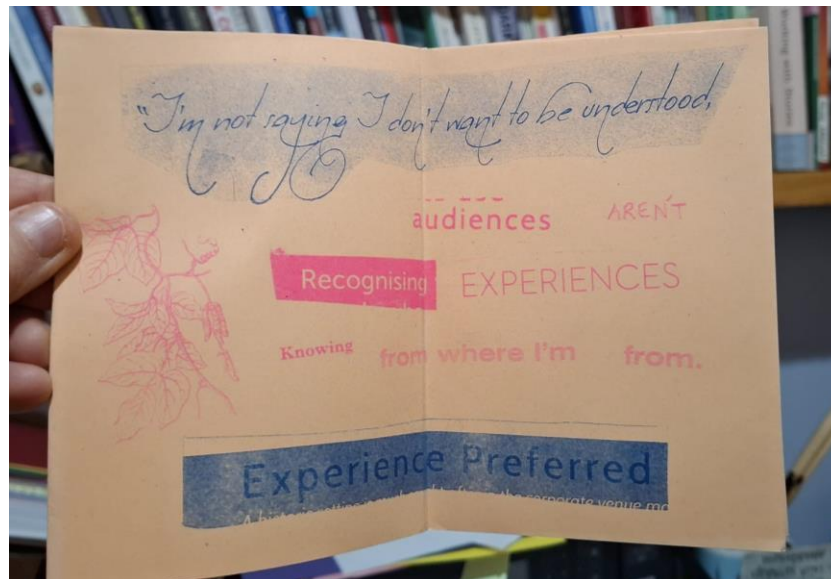


Image 3.5 a zine reflecting on standpoint theory and the value of subjective experiential knowledge

Reflecting on my experiences of participating in mental health research as a survivor afforded me insight into how zines might help tackle the epistemic injustice experienced by survivors in research. For example, I recalled that I had included, in a zine-like text, testimony that I felt had been excluded from research that I took part in as a survivor participant (Walker, 2016). This helped me to understand how survivors might feel silenced in research and how I might avoid this in my own research (see images 3.6, 3.7 and 3.8 from a zine I made as part of this reflective process).



Image 3.6 Cover of zine reflecting on my experience of participating in research as a survivor

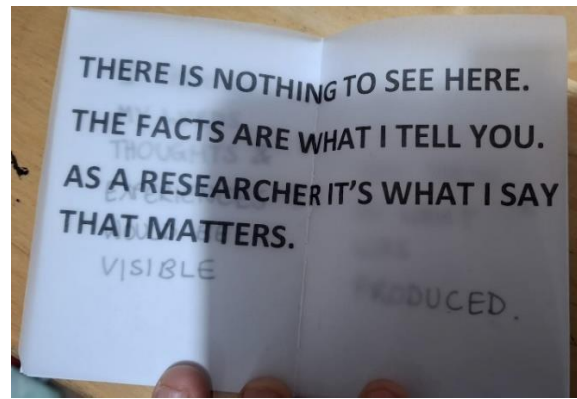


Image 3.7 Pages from a zine reflecting on my experience of participating in research as a survivor

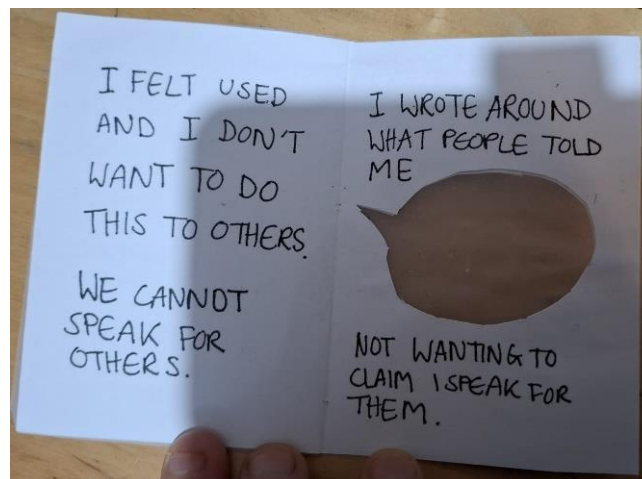


Image 3.8 Pages from zine reflecting on my experience of participating in research as a survivor

Using zines as part of my process of reflection was a good way to remind myself what it was about zine-making that I find so helpful when trying to reflect on, and articulate, my experiences. In addition, it enabled me to identify which zine qualities afforded me the opportunity to create and share accounts or experiences which I felt I had been prevented from sharing, which were different from the accounts I was aware of, or which I'd found difficult to create and share in other formats and settings. In this way, my own zine making helped me to develop prompts for interviews with survivor zinesters in the next stage. For example, it led me to include a prompt about links between the process through which zines were created and

their contents, and some separate prompts about participants motivations for creating and sharing zines. I wouldn't have done this if I hadn't first reflected on how helpful some qualities of the zine-making process were to me, or how my motivations for creating zines were not the same as my motivations for sharing zines. I draw on my personal reflections about my zine-making throughout this thesis as it is part of my data.

Reflecting on my own experiences meant I didn't ask participants anything I hadn't asked of myself. In this way, I tried to create reciprocity in my relationships with participants and to reduce the asymmetry that can occur in relationships between researchers and participants (Von Vacano, 2019). Reflecting on my own experiences also helped me to generate useful ideas which I used to inform the rest of my research. For example, these reflections led me to decide to invite participants to respond to my initial analysis and my final analysis and to give them the opportunity to have their responses included in my thesis.

Reflection on the ethics review process

Whilst I was carrying out my initial reflections, I applied for approval from the university ethics committee to carry out interviews with participants in stage one and interviews and workshops with participants in stage two. Given that the research was begun during a global pandemic, this included outlining how I would respond to Covid-related restrictions on face-to-face meetings and how I would reduce the risk of participants catching Covid, as well as how I would identify and make adjustments for participants with differing needs, and ensure they had information about available support systems. These things were important to consider given that research cannot be truly participatory if it does not account for participants differing needs and communication styles/preferences, and given that survivors might have found it distressing to talk about their experiences.

I was granted ethical approval for the research¹⁶ (see appendix 3 for approval letters) but I have chosen to include a few reflections on some of the reviewer's comments to my initial application for ethical approval. I found these comments interesting as they highlight the ways in which survivor knowledge (and zines) might be viewed, marginalised and excluded from research. For example, reviewers expressed concerns that zines might "cause the audience to make poor decisions regarding their health" because they were "uncensored" and didn't make use of "empirical materials". One reviewer expressed concern about me having a "critical approach to the medical model of mental health care" and, despite acknowledging it was outside their remit, the same reviewer questioned the quality of the research on the grounds that there was no "research hypothesis or null hypothesis". These were fascinating responses as they appeared to echo some of the problems survivors face in the mental health (MH) system, as outlined in my survivors and zines chapter. For example, they indicate how survivor knowledge which might challenge the position, expertise, and balance of power of clinicians might not be valued in the MH system (Felton and Stickley, 2004). These responses were also fascinating because they implied that knowledge shared in zine form should not be valued or trusted, much in the same way that survivors' testimony is often not valued and trusted in the MH system (Grim *et al.*, 2019; Morant *et al.*, 2015; Crichton *et al.*, 2017; Rogers and Pilgrim, 1999) or research settings (Rose and Kalathil, 2019; Faulkner, 2017). Indeed, the criticism of my research approach seemed to echo the ways survivors are disadvantaged by the prevailing epistemology and ontology of the MH system (Rose and Kalathil, 2019; Crichton *et al.*, 2017; Scrutton, 2017).

I reflected on these responses in a zine called *Truth Knowledge Power*¹⁷. When I sent this zine to a friend, they recommended I read Miranda Fricker's (2007) book *Epistemic Injustice: Power and*

¹⁶ Ethics Approval ref: BAHSS2 0158 Stage 1

Amendment to do face to face for stage 2 ref: BAHSS2 0158 Amendment_12Aug21 [F2F]

¹⁷ This zine is now held at the Wellcome library's zine collection

the Ethics of Knowing. As a result, I decided to frame my thesis around the notion of epistemic injustice and this, in turn, led me to other theories about epistemic injustice which are now threaded throughout this thesis. Therefore, I have much to thank the reviewers for.

Survivor zinesters and their zines

For the next step of my research, I recruited eleven survivors who made and shared zines. These zinesters were all survivors of the mental health system in the sense that they all they had all been in receipt of mental health services, specifically they had all received psychiatric diagnoses and/or been in psychiatric/statutory mental health services. They were recruited through contacting zinesters who had zines in the zine catalogue that the wider MadZines research project was developing, and through word of mouth and 'snowballing' with survivor zinesters telling me they knew of other zinesters who wanted to take part. Initial contact was made via direct messages on social media or email. This stage took place at the start of the Covid pandemic when in-person contact and events like zine fairs were not taking place and, in fact, not allowed by Government or University guidelines. Difficulties with recruitment meant that I had to include people who accessed voluntary sector mental health support as well as those with extensive histories of statutory mental health services.

As a woman I was particularly interested in the experiences of other female survivors. In addition, as outlined in my survivors and zines chapter, whilst there is some evidence about women articulating and sharing knowledge via zines (Piepmeier, 2009; Dudley Shotwell, 2016; Bates and McHugh, 2014; Chidgey, 2006; Guzzetti and Gamboa, 2004), there is scope to discover more in relation to female survivors' experiences of making and sharing zines. Therefore, I initially tried to recruit women, but I later widened this to include non-binary people who were interested in taking part. I did so because during the process of the research one person came out as non-binary and another, when later asked how they'd like to introduce themselves, described themselves as non-binary. There is also some evidence that non-binary people use zines to articulate and share knowledge (Daniels, 2022; Mahr, 2018) and there is

scope to discover more in relation to non-binary survivors' experiences of making and sharing zines.

It has been argued that using pseudonyms in research can erase participants' contributions rather than protecting them (Brear, 2017; Moore, 2012), and Scarth (2015) noted that participants in their study wanted to use their real names to preserve ownership of their words and maintain a public connection to their identity. Similarly, Zabeeh (1968) connects naming and power and Lahman *et al.* (2015) suggest that research participants should be able to choose their pseudonyms.

With this in mind, all participants in both stages of the research were given the choice of whether to be named or referred to using a pseudonym. They also all chose whether to have their zines named or referred to via an agreed description. In this way, they chose how their contributions were recognised and acknowledged. Where pseudonyms are used in this study the pseudonyms were chosen by participants. In addition to providing participants with information about my research and gaining their consent before they took part, I made it clear that they could change their mind and opt out if they so chose. Indeed, there was a person I interviewed in stage one who decided shortly after the interview to withdraw her data from the study.¹⁸

The interviews at this stage were exploratory, semi structured, in-depth online interviews which loosely drew on narrative research interview methods to create space in which participants might introduce their own ideas (Reissman, 2008). Anderson and Kirkpatrick (2016) outline how narrative interviews can benefit from having a semi-structured element and Andrews *et al.* (2013) claim that "most experience centred narrative interviewing is semi-structured" (p.55).

¹⁸ I'm not sure of their reason for withdrawing.

The interviews were all conducted online due to Covid restrictions. Most interviews were conducted via Microsoft Teams (the platform used by the university), but two of the participants (Kira and Lisa) chose to answer questions via email instead. I invited participants to reflect on and tell me about their zine-making and sharing process and I used prompts to elicit information about the relationships between making and sharing zines, and sensemaking, awareness raising and community (see appendix 4 for interview prompts).

The prompts used in the interviews were open ended to help establish “a climate that allows for story telling in all its forms” (Reissman, 2008, p.23). I attempted to listen to interviewees in an emotionally attentive and engaged way. Reissman (2008) notes that when we listen in an emotionally attentive and engaged way, we open ourselves to new possibilities, new knowledge and ways of understanding. She writes that the “wording of a question is less important than the interviewer’s emotional attentiveness and engagement and the degree of reciprocity in the conversation” but that “open ended questions are more likely... to provide narrative opportunities” (Reissman, 2008, p.24).

Whilst the prompts provided a guide, I tried to allow the interviewees as much space as possible to introduce things I hadn’t planned for or expected. I also wanted to encourage greater equality in the interview process. Reissman (2008) has described narrative interviewing as “following participants down *their* trails” and argues that by giving up the control of a fixed interview format, researchers can encourage “greater equality and uncertainty in the conversation” (emphasis in the original) (p.24). My interviewees used the space to tell me about important aspects of their experience that I hadn’t planned for or expected. For example, they questioned certain ideas I’d held about “raising awareness” and told me what terms like that meant to them, and about the impact that reading zines, and being part of the zine community, had had on them and their lives. My initial assumption was that zines might be a tool with which survivors could raise awareness of our experiences. However, in the first few of the initial

interviews, participants brought to my attention the difficulties with the idea of 'raising awareness' and introduced the idea that the zine community might be a collective knowledge making space. For example, in response to my question about raising awareness, Lisa said:

"I think, with making zines, they are going to be read by a very specific community. So, I don't know if they are great for raising awareness"

In response to the same question Annie said:

"I don't know how I feel about awareness raising 'cause it [making and sharing zines] feels queer[and] zines are quite contained to their own community [and] raising awareness sounds a lot more general, a lot more mainstream to me"

In other words, I had been interested in how survivors might use zines to share their knowledge with people in positions of power, but it became clear that this was not necessarily what survivors were doing, or wanted to do, when they made and shared their zines. I therefore altered my questions to reflect this in later interviews. For example, I stopped asking how survivors might use zines to raise awareness of their experiences. Instead, I asked them how and why they used zines to share their experiences, and about their experiences of community. This allowed participants to talk about awareness raising if it was relevant.

I hadn't planned on using their zines as 'data', but it became clear during the process of contacting and interviewing participants that their zines were an important part of their narratives about using zines to articulate and share knowledge. Unsolicited, most participants emailed their zines to me in advance of interviews, offered to post them to me, and held their zines up to the screen as they spoke. Bell (2013) referred to a similar experience where someone she was interviewing introduced a photograph. She describes how it hadn't occurred to her that a photograph was necessary to understanding the interviewees experience, whereas

she later came to wonder what she had missed “by attending only to what she had said and how she had said it” (p.143).

The zines themselves, and the process of my reading them, provided insight into the mechanics of creating and sharing zines and how this can work as a sense-making process and as a way to share knowledge. Using zines as data meant valuing what participants had chosen to share with me and the form in which they had chosen, or felt able, to share it. This is consistent with PAR interviews where “participants are given maximum opportunity to present events and phenomena in their own terms” (Stringer, 1999, p.70). It is also consistent with how PAR researchers collaborate to establish what are the most appropriate methods of data collection (Gillis and Jackson, 2002; McNiff and Whitehead, 2006; Stringer and Genat, 2004).

Including zines in my data enabled participants to share things with me that they might not otherwise have shared, and it helped me to gain insight into how zines might represent participants ideas, experiences and understandings. The zines illustrated and/or clarified what participants told me and combined with what the participants told me. Reissman (2008) has noted that “sometimes it is next to impossible for participants to narrate experience in spoken language alone” (p.26). Similarly, Rich (2002) argues that people can make statements with images that cannot be fully made with words or quantified with numbers, and Pryce (1996) argues that the visual domain allows researchers to gain powerful insights into “representations and codes of meaning” (p.109).

Initial analysis of stage one

Drawing on PAR, I undertook multiple reflective processes at different stages of the analysis, revisiting my data and adjusting my methods as I gained new insights. In line with PAR, my process was iterative in that I went backwards and forwards between the themes, and my data, and used this process to refine my themes. I used what I learned from survivors in this stage to help me plan the next stage. Although zines are included in my data, I avoided analysing the

content of the zines because zines are one of the few places where survivors can create and share narratives without interference from others. This was in line with the approach taken by the MadZines project as a whole, which sought to avoid “imposing our own one-way interpretations on other people’s words and images” (Spandler and Anderson, 2021). Instead, I used zine-making to analyse what survivors told me in interviews and communicated through their zines. The first process of zine-making drew on narrative analysis and the second drew on thematic analysis. I outline each, in turn, in the following sections.

Narrative zines

First, I made narrative zines about each individual participant and their zines. In response to recognising that their zines were part of the narrative they were sharing with me I created zines which combined the individual interviews with the zines each individual shared. This involved a close reading of individual transcripts, and the zines they referenced and shared, and enabled me think about each zinester’s zine-making process(es). See images 3.9, 3.10 and 3.11 below for examples of front covers and sample pages of the narrative zines I made.

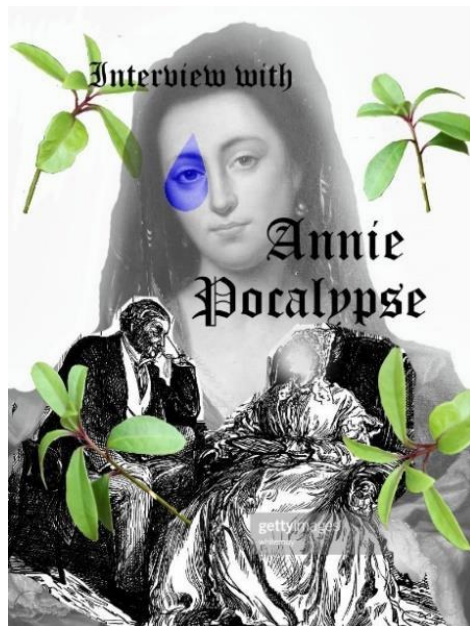


Image 3.9 Cover narrative zine Annie

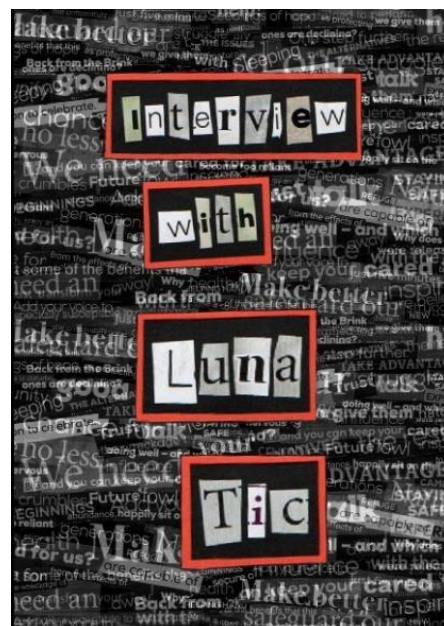


Image 3.10 Cover narrative zine Luna

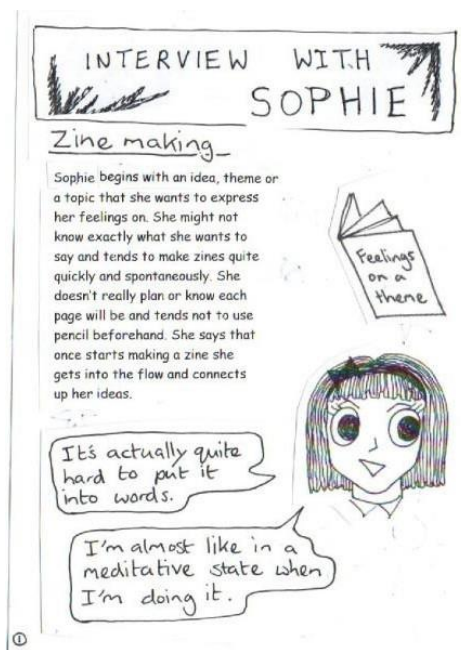


Image 3.11 Cover narrative zine Rosie

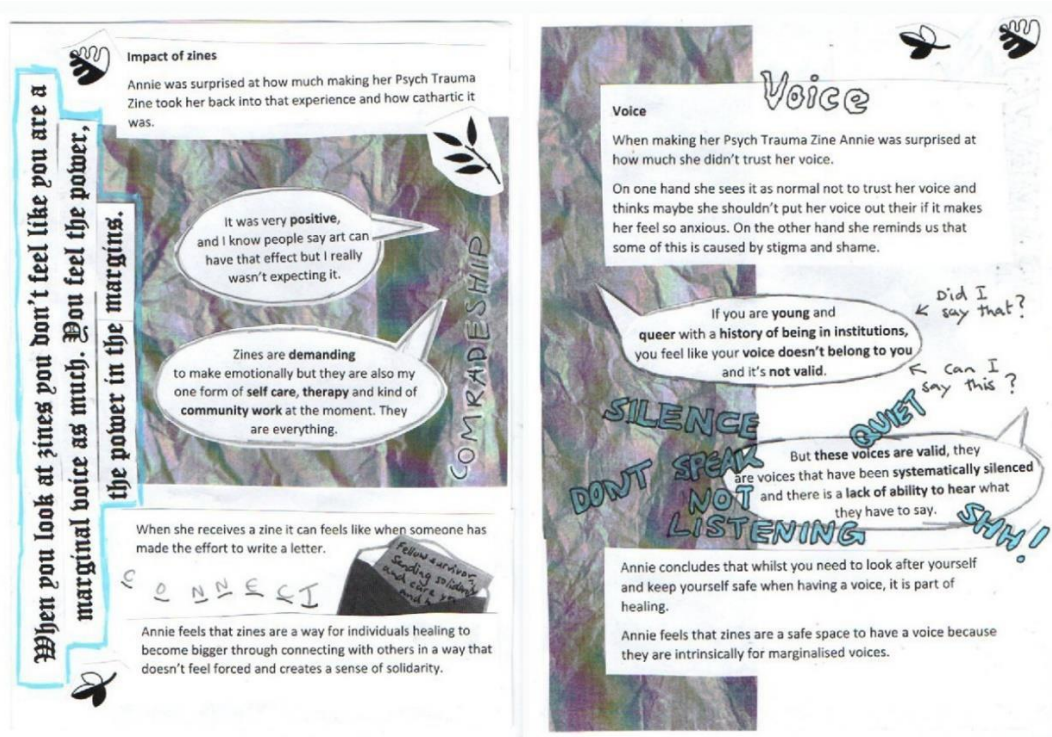


Image 3.12 sample pages narrative zine Annie

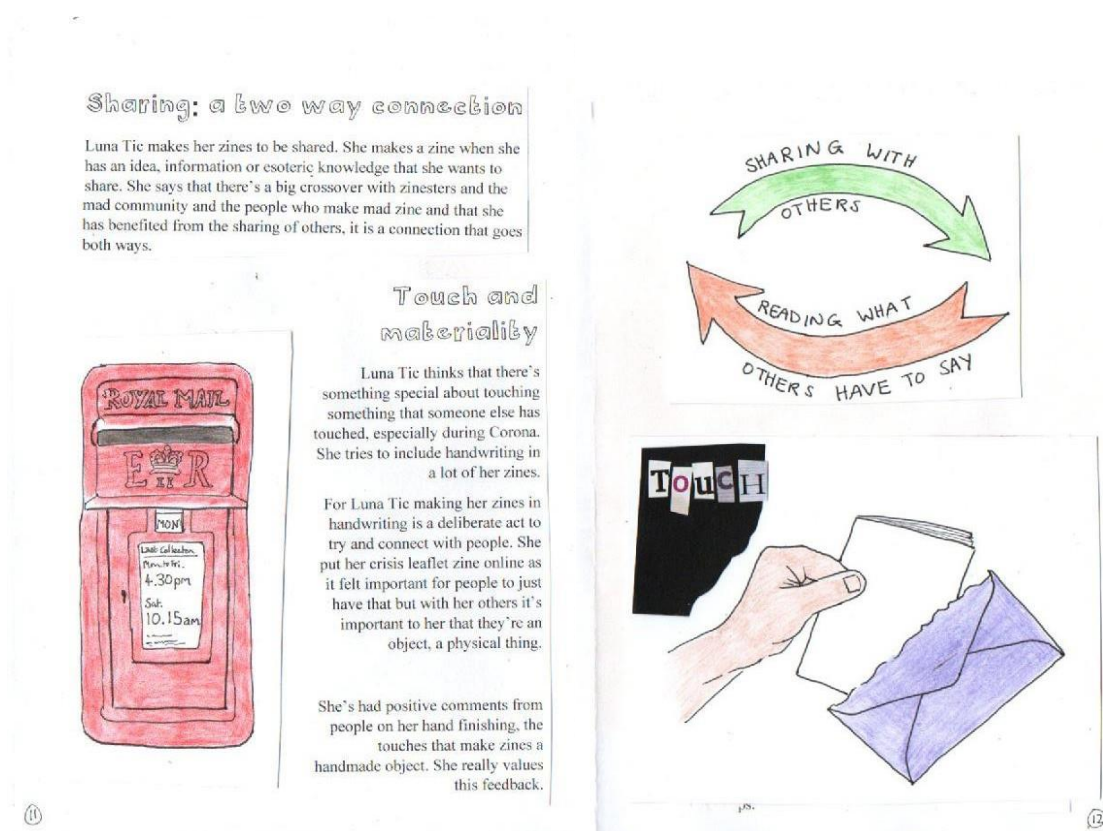


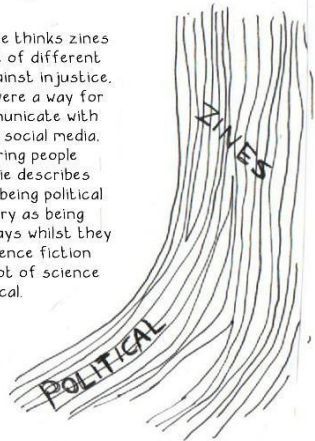
Image 3.13 sample pages narrative zine Luna

Don't use the 'P'-word

Sophie says that whilst what she does with her blog and her zines is very political she never uses that term. Sophie says when people hear the word political they think it will be boring and not relevant and don't want to hear it.

Political Roots

Sophie says she thinks zines were a key part of different movements against injustice, because they were a way for people to communicate with each other pre social media, and a way to bring people together. Sophie describes their roots as being political and their history as being political. She says whilst they also have a science fiction background a lot of science fiction is political.

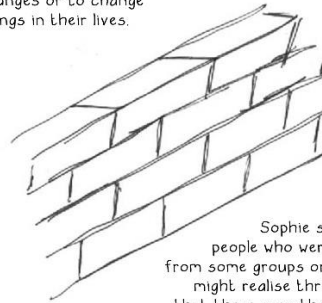


It's not just me.

Sophie says that another thing that zines can do is bring people together or show people that they're not alone.



She says if you realise, you're not the only one going through something, then you realize you have allies. Sophie says she's thinking of disability activists and suggests that people can then come together to make changes or to change things in their lives.



Sophie says maybe people who were excluded from some groups or activities might realise through zines that there are other people in their town or society who face similar barriers and then they could join together.

(5)

Image 3.14 sample pages narrative zine Rosie

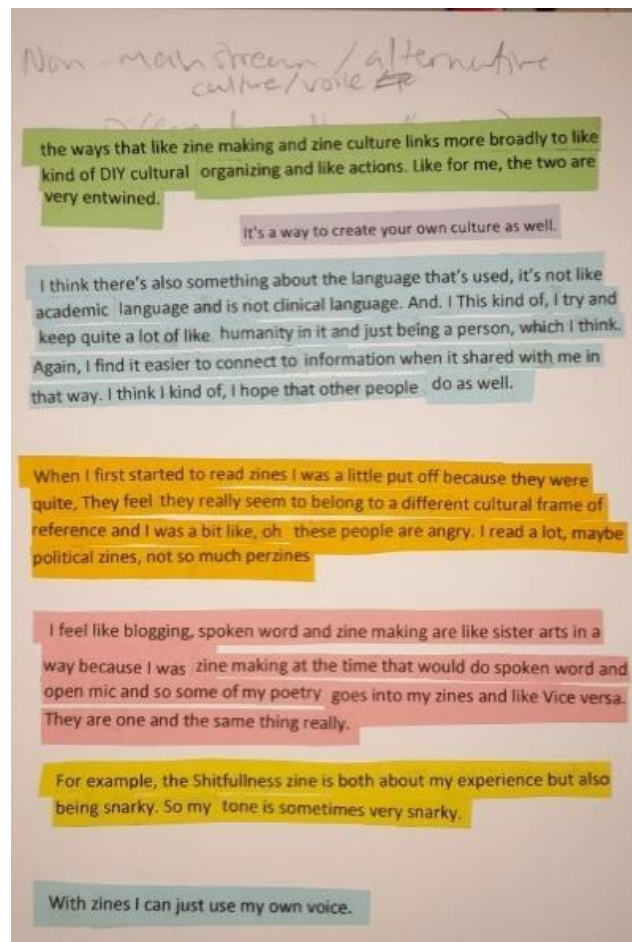
As part of this zine-making narrative analysis I tried to recreate the style and structure that the individual zinesters used and the same materials and similar processes they described using. The titles, subtitles and some of the images in the zines were essentially codes for the transcripts (i.e. they described key concepts or the links between the bits of information they were ascribed to) whilst the way I created each zine coded for zinesters' style, structure, and creative process. Through this process, I was able to see the entirety of what individuals had shared with me about their experiences with zines and the ways in which what they told me in their interviews related to what I could see in their zines (and vice versa). This method also helped me understand participants' zine-making processes on a more visceral level. It highlighted the differences between individual's use of zines, the processes they used, their motivations and their relationship with zines. It helped me see how different zinesters made use of different zine qualities to achieve their aims and it fed into my later process of analysis.

Zines on themes

For the next stage of my analysis, I looked for themes across the interview transcripts because I wanted to understand more broadly how survivors used the process of creating and sharing zines. This process involved creating memos of things that stood out to me: because they seemed especially pertinent to my research aim and objectives; were surprising or unexpected; similar to my reflections or literature I had read; or because they generated phrases or images that stayed in my mind. This method mirrored the processes of scrapbooking and diary writing that some of the zinesters spoke to me about, such as gathering notes, pictures and ideas before beginning to make a zine.

When making zines, I often print out different elements and move them around to see how they might link to each other. I did the same with quotes from the interview transcripts and the descriptive memos I had made. This enabled me to look for patterns across the different interviews, to think about how codes might relate to each other or how they could be grouped together. In this way, I began to identify themes.

Of the themes that emerged, I chose to focus on the three which related most closely to my research objectives and the gaps in literature I had identified. I then revisited my transcripts with these three themes in mind, cutting out quotes from transcripts and sticking them on pages to see if the themes I was using were still representative of the detail of the transcripts. I used different colour paper for each zinester so I could see at a glance who had said what. In this way, themes could be identified without individual differences being obscured (although it did also mean that quotes were no longer embedded in their individual narrative). See example below (image 3.15).



3.15 Revisiting transcripts

The process of revisiting transcripts with the themes in mind led me to rename themes so that they better represented what was in the transcripts e.g. “an action” became “bringing to light” and the other themes were renamed as “making (un)common sense” and “doing community”. I then made zines on each of the three themes (see image 3.16 for front covers of these zines). This involved bringing together quotes from survivor zinesters on each theme, organising and annotating them on the pages of the zine (see images 3.17 and 3.18 for examples of this).

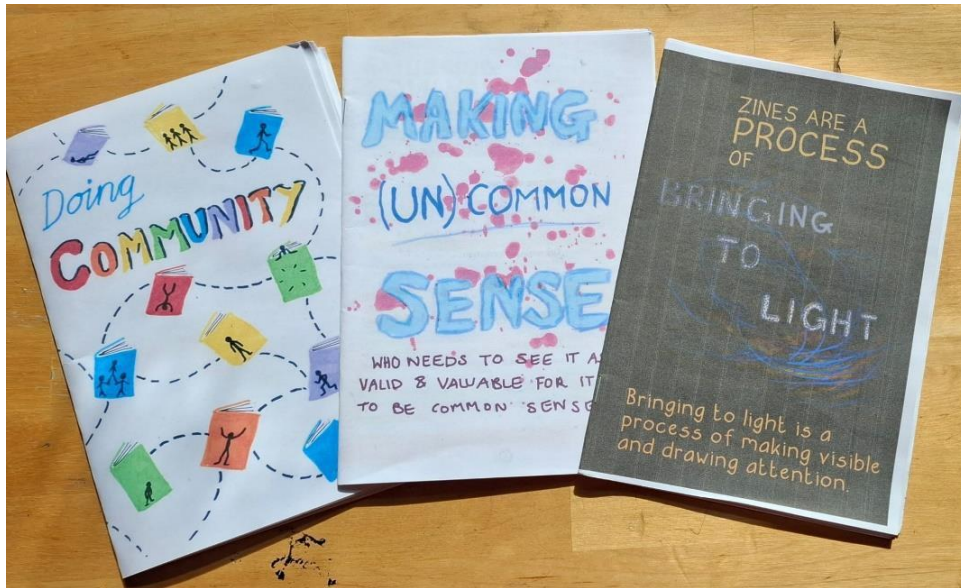


Image 3.16 Zines on themes

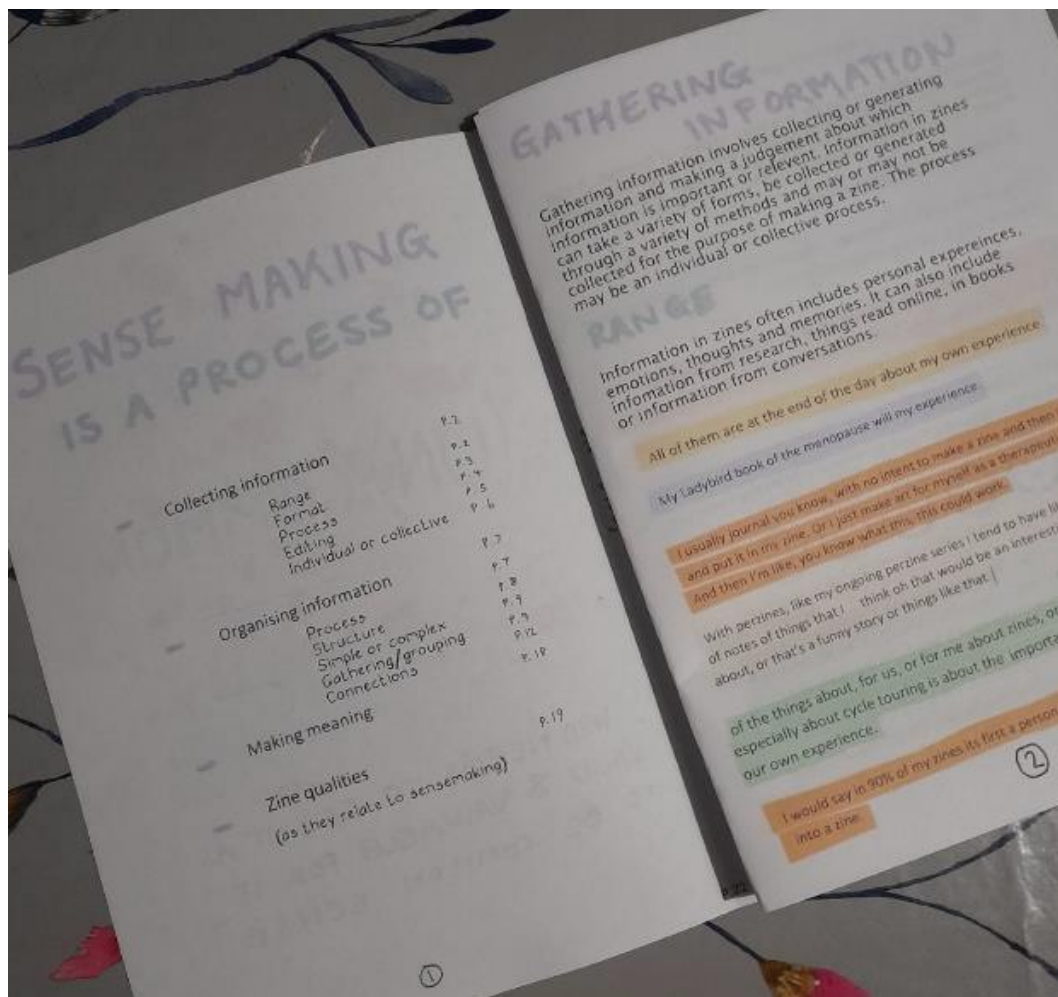


Image 3.17 sample page from Making Uncommon Sense zine

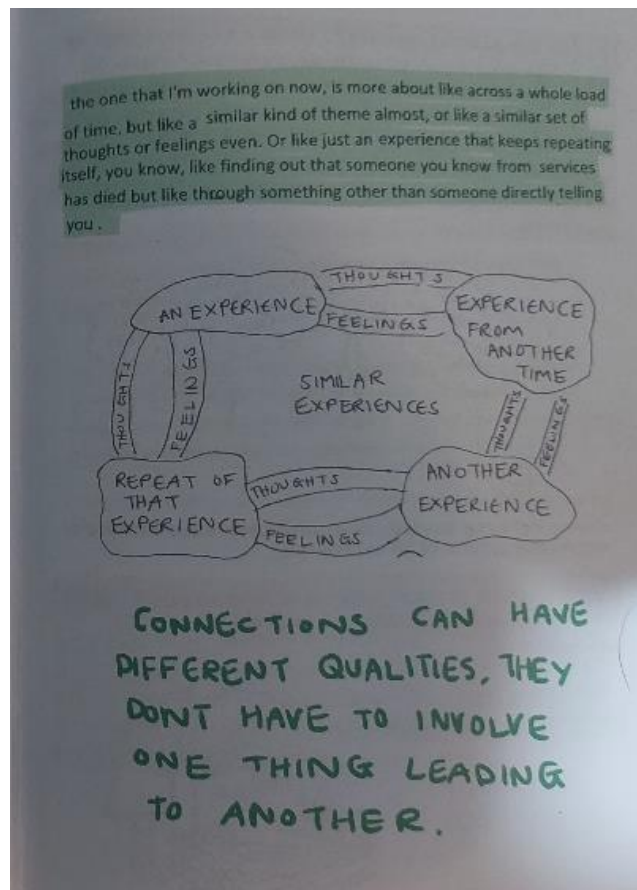


Image 3.18 Sample page from *Making Uncommon Sense* zine

Through the process of making zines on themes it became clear that some survivor's experiences of, and familiarity with, zine communities enabled them to create and share knowledge, and that the qualities of zines and sharing them, in turn, fed into their experiences of this community. This process also highlighted the two-way dynamic relationship between these survivor zinesters and the zine community. If I had begun this process of analysis by looking through my data for ways in which zine qualities (and possibly the zine community) directly affect what can be articulated and shared this is unlikely to have become clear. It was possible to identify this and then think about how this might relate to tackling epistemic injustice because I began my analysis by looking for any data which might relate to how and why and to what effect survivors made and shared zines, and then identifying patterns.

Through this process it also became clear that understanding the relationship between the themes of “Making (un)common sense”, “Bringing to light” and “Doing community” and the qualities of zines were key to understanding what zines (can) do. To explore this further I made an additional zine drawing together the things zinesters had said about zine qualities and further exploring the possibilities and limitations of zines in relation to all three processes. Through reflecting on these thematic zines and revisiting my questions I refined and clarified the emerging themes. See appendix 5 for *zine qualities* zine and below for the front cover (image 3.19) and a sample page (image 3.20).

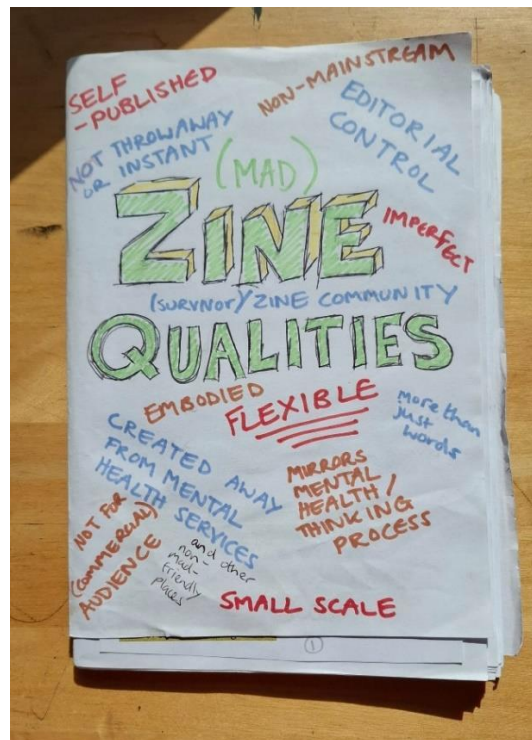


Image 3.19 Zine qualities zine

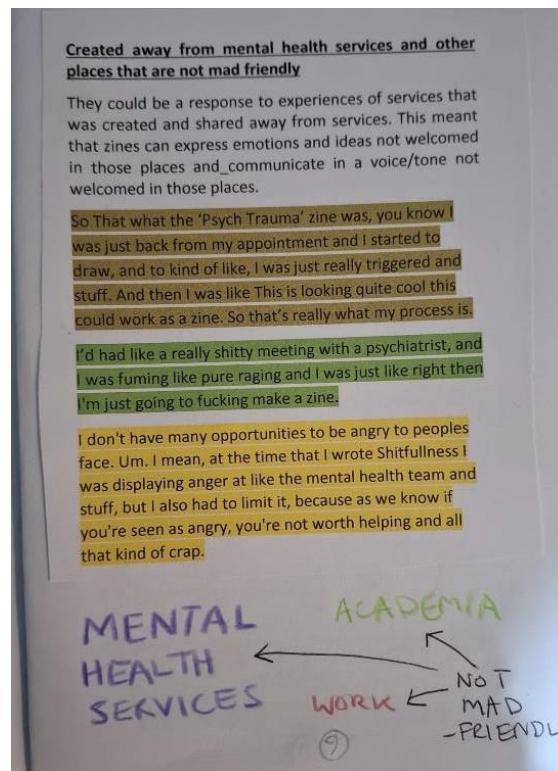


Image 3.20 Sample page from zine qualities zine

I shared the zines I made as part of this initial process of analysis with participants from this stage who said they would like me to do this. I invited them to comment on these because I wanted them to have the opportunity to challenge, add to, or confirm my interpretations. However, the only responses I received to these zines were a few participants who thanked me for making them and sending them and said they really liked them. I took this to mean these participants didn't feel I'd misunderstood or misrepresented them.

I used what I'd found out from the first stage of the research to feed into the second main stage of the research where I introduced zine-making to survivors who hadn't made zines before and/or hadn't heard of zines.

Stage two

For this stage I recruited five survivors who hadn't made zines before and/or hadn't heard of zines. They were all survivors of the mental health system in that they had all accessed mental health support, for some of them this was via statutory services including inpatient services and

for others it was voluntary sector services.¹⁹ I wanted to explore how their experiences compared to the survivor zinesters I had spoken to in the first stage and whether introducing survivors to zines might result in them gaining some of the benefits the survivor zinester in stage one described.

The survivors I recruited for Stage Two were all multiply marginalised, i.e. marginalised not only on the grounds of their mental health/survivor status but also in other ways. This was important because many people in the mental health (MH) system are multiply marginalised, especially in relation to social class, gender, ethnicity, poverty etc, and these factors often contribute to mental health issues (Dougall *et al.*, 2024; Jongsma *et al.*, 2021; Cruz-Gonzalez *et al.*, 2023). In addition, marginalised survivors can be further disadvantaged by failures to address intersecting systems of inequality in the MH system (Cooke and Kothari, 2001; McDaid, 2009) and therefore may be particularly epistemically disadvantaged in the MH system. As I mentioned in my survivors and zines chapter, Reynolds (2019) has suggested that zine culture can be exclusionary; she describes it as very white and draws attention the fact that it takes time and money to create and share zines. This sentiment was echoed by a participant, Kirsty in the first stage:

“I am interested in the ways in which zine culture replicates, can replicate dominant culture. It’s still really fucking white, and I’m interested in that and what we do about it.”

It is therefore important to try and understand multiply marginalised survivors’ experience of zines and epistemic injustice. By focusing on marginalised survivors in Stage Two I hoped to

¹⁹ As outlined in my introduction there are similarities across the MH system., People’s needs (and sense of dependency) may be similar. Professionals with a range of orientations can be found across the MH system. Additionally, although vol sector services don’t physically restrain and section people many have policies of contacting other services who can do this if they believe a person to be a danger to themselves and/or others.

explore this further, as well as explore what opportunities zines might afford survivors who are multiply marginalised.

The five survivors I recruited for this stage were multiply marginalised in the following ways:

Diane is a working class care leaver of colour in a same sex relationship, living off benefits in an area of high deprivation; Bex has a marginalised sexuality and is living on benefits in an area of high deprivation; Kaz is a working class queer woman living in an area of high deprivation; Nicola is a working class woman with a physical disability who is living on benefits in an area of high deprivation, and Nazrah is a working-class disabled Arab/Jewish woman of colour living on benefits in an area of high deprivation.²⁰ Along with participants from stage one, the participants from this stage introduce themselves in their own words in the following chapter.

I recruited participants for this stage via voluntary sector services they were attending for support. These were all services that were local to me and which I had connections with through my previous work in a voluntary sector mental health service in Calderdale, West Yorkshire. Recruiting participants via services meant that if they experienced difficulties, they could access support which was important because it was possible that some participants might find talking about their experiences distressing or difficult. This was agreed with the ethics committee. Whilst it could have been possible participants didn't experience the service they were accessing as helpful; my experience suggests that if people aren't benefiting from a service in the voluntary sector, they stop accessing it and my sense was that the participants did experience the services I contacted them through as helpful.

Other than Nicola, all the participants in stage two described not being listened to or heard in various settings because of their mental health status and being mental health service users. In addition, all participants linked their mental health difficulties and ways of thinking and experiencing to difficulties in articulating and sharing their experiences. In other words, other

²⁰ Where I have referred to their social class this is how the participant described it.

than Nicola, they all described experiencing difficulties similar to those that the literature has shown that survivors experience in the MH system²¹.

I had initially envisioned recruiting a group of survivors via a single support organisation, but this was difficult because services were only just starting to return to face-to-face contact with clients as Covid restrictions were being reduced and many people were still anxious about any face-to-face contact, let alone being in a group in person. Consequently, I ended up recruiting one participant through a mental health service I used to work at in Calderdale, two people from a women's centre I had had been a trustee for, and two from a support group in Halifax that I knew through my previous work. Unfortunately, this reduced opportunities for participants to discuss and reflect on their experiences as a group because they weren't an existing group, and I wasn't able to facilitate zine-making sessions as a single group.

The five participants recruited for this stage took part in the following: an initial interview, zine-making activities, a mid-process interview, a zine sharing opportunity and then a final reflective interview. I recorded and made notes about the zine-making and sharing sessions and interviews, which I used as data for the research. I also included the zines they made as data because their significance had become evident in the earlier stage.

Initial interview

I used this interview to start to understand participants' experiences of epistemic injustice, to find out what participants hoped to gain or achieve from taking part in the research and what they thought might help facilitate this. In addition to being a way to gather data, these interviews were a way for participants to direct the process they were to be involved in. Before each initial interview I ensured that participants were aware of what support systems were available to them and I made it clear to participants that their participation/non-participation/withdrawal

²¹ It is perhaps not incidental that the participant who didn't describe experiences of epistemic injustice was the participant who had the least contact with the mental health system.

from the research would not in any way affect their use of the service. I made notes immediately after the interviews.

I asked participants if they ever felt that what they shared with people wasn't valued and if they ever found it difficult to reflect on, articulate and/or share their experiences. I also asked them what they hoped to get from being involved in the research process, what they wanted to achieve through making and sharing zines, how they might like to do this, and what resources they would like me to provide in the zine-making workshops. I also asked them what they thought they might like to make their zine about, which helped people think about what they might like to achieve through the process. Their responses helped to shape the zine-making sessions. For example, I provided the resources they asked for and ran the sessions according to their preferences. This included enabling one of the participants (Nazrah) to take part in a zine-making session with just me, as she was worried about catching covid.

Zine-making sessions

I facilitated zine-making workshops to explore survivors' zine-making processes and activities. They were also a way to introduce participants to zine-making and provide resources with which they could make zines. The data gathered from these zine-making sessions took the form of audio recordings and notes I took after the session. I used audio recordings instead of video as this felt less intrusive and less distracting and I made notes after the sessions. instead of during them, for the same reason.

The workshops were all held in person because this is what the participants said they would prefer. The venues I used for the workshops were the venues of the organisations that the survivors attended for support because these venues were familiar and accessible to participants, as well of being free of charge. Participants were invited to make zines about a topic of their choice using materials and creative processes of their choice. This was important as survivors in the first stage had indicated that one of the important aspects of making zines

was that they could choose what their zines were about and how they made them. In addition, as outlined in my literature chapter, survivors can find themselves in the position of being unable to set the agenda in the MH system and I didn't want to recreate this dynamic.

There were two participants in most zine-making sessions although, as already mentioned, Nazrah chose to do a zine-making session with just me. Attending zine-making sessions in pairs gave these survivors the opportunity to share their zines with each other in the session. One of the consequences of one person doing zine-making with just me is that this person didn't have other participants to share their zine with although they did share their zine with me. Four of the participants attended four zine-making sessions although the participant who was making zines on her own only attended a single zine-making session. The number of sessions was decided in conjunction with the participants concerned before the sessions began; depending on what time they could commit to, what they thought they would enjoy, and how long they thought it might take to create their zine.

Mid process reflective interview

These interviews were an opportunity for survivors to reflect on their experiences of zine-making. It was another opportunity for participants to direct the process they were involved in as well as being a way to gather information about their experiences. I asked participants how they'd found the process and what they might like to do next. If or when they spoke about sharing zines, I raised different possibilities for this. Four were interested in meeting participants from the other zine-making sessions and sharing their zines with them. So, I arranged for these four participants to have the opportunity to share their zines with each other. One participant said she thought the service she was criticising should read the zine, but they wouldn't be interested, so I tried to create an opportunity for her to share the zine with that service, but this was unsuccessful.

Zine sharing session

This zine sharing session gave me an opportunity to explore survivors' zine sharing processes and activities. In similar way to the zine-making workshops, the data gathered from the zine sharing session was in the form of audio recordings and notes written directly after the sessions finished.

This session was held in person at the venue in Halifax where some of the zine-making sessions had taken place and where two participants normally attended a support group. It was in person as this seemed the most practical way to share some of the zines and the venue was chosen as this worked best for physical accessibility and other possible venues wouldn't meet the access needs of one of the participants. One of the consequences of using this venue was that some of the participants were more familiar with the venue and so more comfortable than others. Four participants planned to attend but, on the day, one was ill so only three people were able to attend. With her permission, the zine made by the person who was ill was shared in the session and she received responses via post as she indicated she would like to take part in this way. All participants kept the original versions of their zines. Participants gave additional consent for me to include images from their zines. It was made clear to participants they could choose for some, all or none of their zine to be included and participants were encouraged to think about the pros and cons of the different options.

Final reflective interview

In this interview I asked participants how they felt about their involvement in the research process as a whole and about their experiences of sharing their zines. During this interview I discovered that some of the participants had begun to share their zines outside of the zine sharing session. You might say they had taken ownership of the process along with the zines they had made. In common with previous interviews this interview was recorded, and I took notes immediately afterwards.

Ethical adherence

In line with what was agreed with the ethics board, in both stages of the research I provided participants with information about the research process, and they had the opportunity to ask questions and give informed consent before the interviews and workshops took place. As part of this process participants in stage two were made aware that their access to support via the service they were accessing would be unaffected by their participation/lack of participation and they were made aware of the time frame during which they could withdraw. In addition, where images of participants' zines are included in this thesis, specific consent was gained from participants for the use of these images.

Analysis

My analysis of stage two focuses on how the identified qualities of zines and the context in which they make and share zines, interact with what survivors (can) do. I focus on how, why and to what effect survivors use zines to share their knowledge, understandings and experiences.

As with the previous stage of analysis, and consistent with narrative research, the analysis was designed to make space to understand individuals' experiences, instead of trying to identify patterns that might be widely applicable. In this way I try to avoid replicating the way the MH system obscures cultural differences and devalues individuals' subjective experiences. I also tried to replicate the focus on individuals' experiences which was important in the wider zine community where many contemporary zines are perzines, zines about individual's experiences (Liming 2010). There were two parts to the analysis at the end of stage two, which I outline below. The first part was based on narrative analysis and focused on the information I had about each stage two participant individually. The second part involved contrasting data from stage 1 and stage 2 and refining the themes from the earlier analysis.

Narrative analysis

Using a similar narrative-based process to the one I used at the end of stage one, but without trying to recreate individuals' style and structure and use of materials²², I created a zine about each of the participants in stage two. Each zine was based on all the information I had gathered

about the individual participant's experiences of making and sharing zines and their experiences of epistemic (in)justice. The process began with the way in which my notes from this stage were organised around individuals' experiences. I brought together information from the first interview about individuals' experiences of not having their knowledge valued and/or finding it difficult to reflect on, articulate and/or share their experiences. I also brought together information I gathered about their experiences of zine-making from interviews, zine-making sessions and their zines, with information about their experiences of zine sharing from interviews and the zine sharing session, and with information from the zines they produced.

For each participant I then identified information that appeared to show how, why and to what effect they were using zines to address epistemic injustice. This included information about which zine(making) qualities helped the individual make sense of and/or articulate their experiences and interpretations; how the power dynamics in which the individual made and shared their zines related to what they felt able to articulate and share; how the qualities of individual zines affected how the knowledge shared in them was received; and how the culture in which zines were made and shared affected how the individual chose to share knowledge and how they expected it to be evaluated. I also identified information about their experiences of epistemic injustice, including epistemic injustice in the MH system. I then organised the information into a zine about each individual's experiences of zines (see images 3.21, 3.22, 3.23 and 3.24 for an example of this).

²² This was because unlike the experienced zinester they hadn't (yet) developed their own zine-style

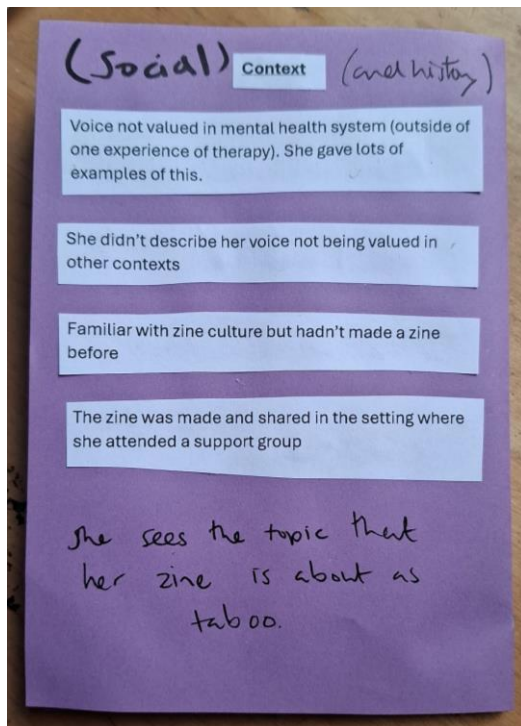


Image 3.21

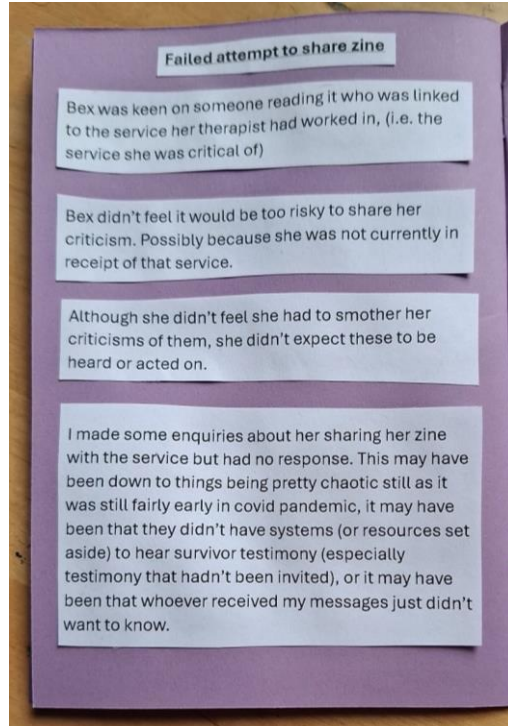


Image 3.22

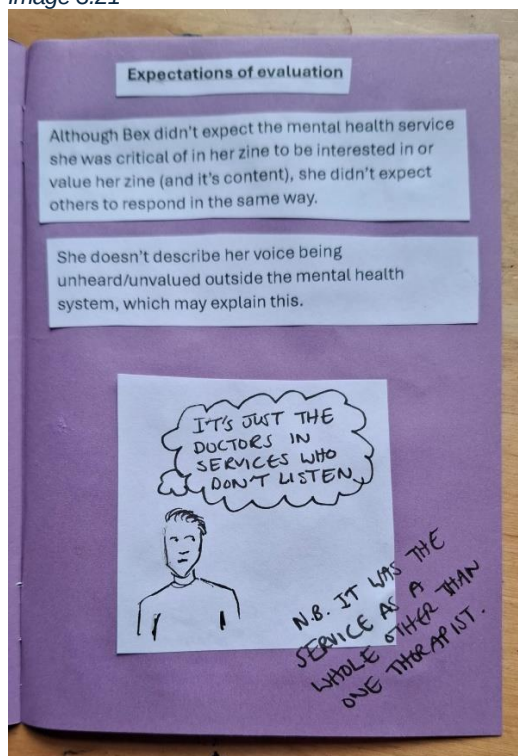


Image 3.23

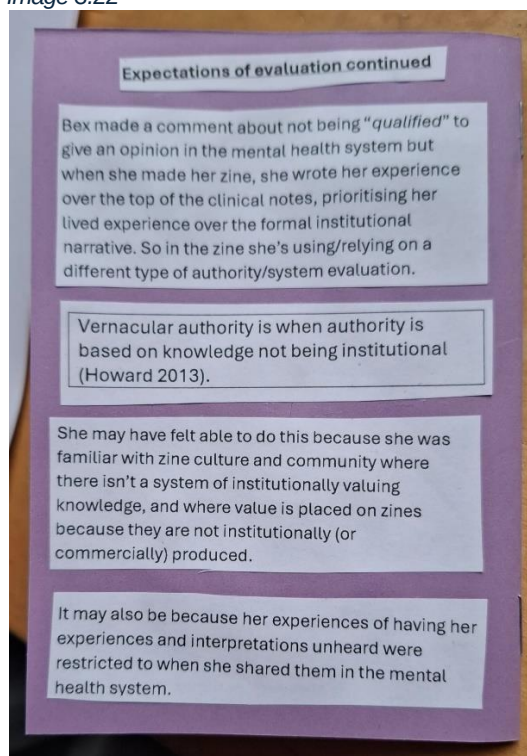


Image 3.24

I used this process to analyse how individuals' experiences of creating and sharing zines might relate to their specific circumstances and context. I kept my research questions in mind whilst

looking for connections between individual participants' experiences of epistemic injustice; their awareness of zine culture; the zine-making processes they chose to use; which zine qualities they found useful, how and where they chose to share their zines; and to what effect they used their zine-making and sharing. I also kept in mind the research context, the specific settings in which participants created and shared their zines and their individual relationships with these settings. I used drawings to further reflect on the relationships I had identified, and these drawings were then added to the zines (see image 3.23 for an example of this).

The drawing process I used here, and throughout my analysis, helped me clarify my thinking and develop my understanding. Like Barrat (2024, p.187), my drawings were “not illustrations of research data to accompany the text, but part of a thought process”. Indeed, all the ideas in this thesis were visualised in my head and/or drawn on paper before I attempted to try and put them into words. For example, I created the following image whilst reflecting on Bex's zine which was about something she felt was taboo to speak about but was able to share in a zine because she could just present it as an art object.



Image 3.25 Reflecting on Bex's zine sharing

Drawing on narrative research helped me to identify differences in experiences that were related to context. For example, it helped identify how participants who were not aware of zine culture, and had extensive experience of their testimony being devalued, used perspectives

that were institutionally recognised to back up their experience and the personal interpretations they shared in their zines, whereas participants who didn't describe their accounts being as extensively devalued didn't do this. It also helped me identify how the only participant from this stage who was familiar with zines and zine culture used her zines to critique some aspects of official communication from the MH system, whereas none of the other participants in this stage critiqued formal information or communication.

I then created more drawings to further develop my analysis. This helped me think about how theory might be usefully applied and to make links between what I had learned from participants and what previous literature has established about survivors and zines. I used this process to think about how theories of epistemic injustice might shed light on the barriers that individual participants face and how and why they might use zines in the ways they do. I used drawings to help me think about: the contexts in which participants created and shared their zines and how these compared to survivors' experiences in the MH system. For example, it helped me to understand why one of the participants wanted to test her readers' commitment to understanding her experience; and why participants might try to gain authority through utilising institutionally produced information. For example, I drew the picture below to reflect on why one participant used official information and quotes from the bible in her zine (image 3.26).



Image 3.26 Reflecting on why one participant used official info and quotes from the bible

Analysis of stage 1 & 2

Finally, I analysed everything I'd collected together from both stages. Building on the narrative process I had just used to understand the experiences of participants from stage 2, I looked to see if the participants from stage 1 (including myself) used zines in similar ways. This led me to refine one of the themes I had developed at the end of stage one. Instead of being about the qualities of the zine community it became about the qualities of the dynamics and culture in which zines were made and shared.

Then, taking the themes I had identified through my analysis at the end of stage one as a starting point, I looked across all the data to compare and contrast my findings about participants from stage two with my findings about participants from stage one. For example, at the end of stage 1, I had identified that there was a link between survivors' position (in the zine community) and what they could articulate and share so I looked for information about the power dynamics in which stage 2 and stage 1 participants created and shared their zines and how this may have affected what they could articulate and share. Like I did in my initial analysis at the end of stage 1, I printed out notes and quotes on coloured paper with a different colour for each participant. Again, this use of coloured paper enabled me to see how many participants chose to share their zines in a particular power dynamic and which individuals did this. I kept moving the information around to enable me to compare participants from stage 2 with participants from stage 1. Making commonality and difference visible can help researchers think about why commonality and difference occurs and what the effect of this might be (Neilson and Kenny 2024). I found this process helped me think through the reasons for the differences/similarities between groups of participants and the effects of these.

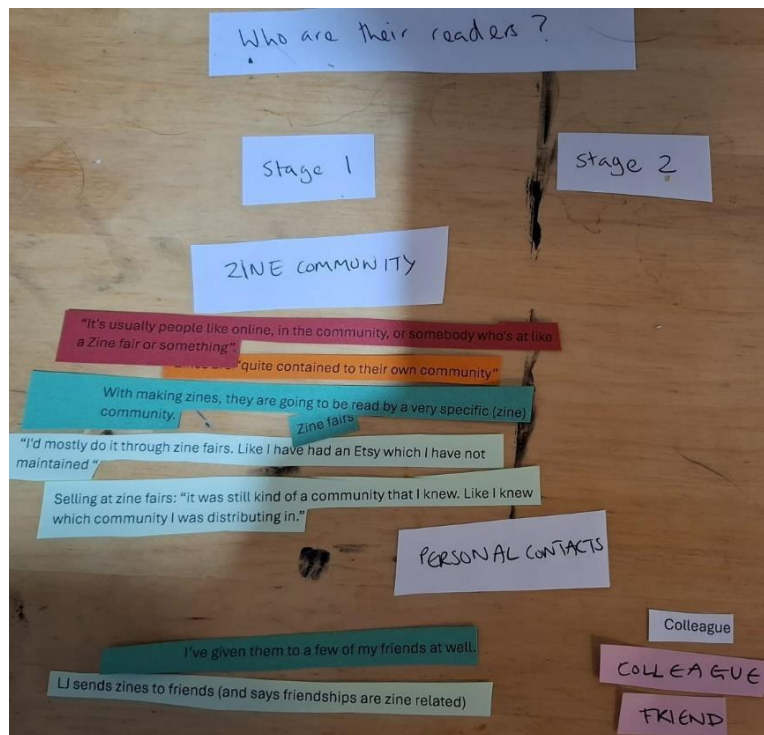


Image 3.27

I then made notes about the patterns and information that were most pertinent to my research questions. For example, I noted where multiple participants had found a particular zine quality, power dynamic or culture to be helpful. I also made note of how, why and to what effect individual participants used different zine qualities, or engaged with power dynamics and cultures, to try and address epistemic injustice. In addition, I made notes of which zines had qualities that survivors had described as helpful and how and to what effect these qualities were used in their zines. Finally, I noted where there were similarities and differences between participants and zines from stage one and participants and zines from stage two. For example, I noted that there were contrasts between whether they chose to share their zines in the zine community, but that their audiences had qualities in common. Focusing on the patterns and themes I had identified, and the data from participants that related to these themes, I then created more drawings as part of my continuing process of reflection and interpretation.

This process helped me think about: non-linear structure as an epistemic resource; how the power dynamics of a zine community might enable some survivors to avoid the risks associated

with sharing testimony in the MH system and enable them to share things they felt they had to 'smother' in the MH system; and how culture/value systems in different spaces affect how zine testimony is evaluated and how participants expect it to be evaluated.



Image 3.28 Reflecting on how participants from both stages prioritised sharing their zines with people outside services who they believed would value them



Image 3.29 reflecting on structures and visual language as epistemic resources

I then brought together all my interpretations for the different stages of reflection, to create a final zine (see appendix 6) before looking through all my data for a final time to see if any of it contradicted my interpretations.

Summary

As survivors are epistemically disadvantaged in the MH system, it was important to use a methodology which doesn't replicate this or reinforce the status quo in relation to knowledge valuation. In addition, because my study is about how zines might be used to address epistemic injustice it was appropriate to recognise and value the ways in which zines can be used to reflect on and share information. Therefore, the methodologies I have drawn on and the methods I used were all chosen with the aim of working towards epistemic justice in research practice. Like the broader MadZines project, I created and used methods which tried to be sensitive to the experiences of survivors and sensitive to zine culture/s. I valued both survivors' testimony and zines as a site of knowledge production within the research process and created opportunities for participants to direct the process they were participating in.

It is my hope that the methods I used enabled the people who participated in the research process to gain something from their participation. I also hope that participants will be able to recognise their contributions in my findings and will feel heard and valued. In my final chapter I reflect on the strengths and limitations of my survivor-friendly zine-centred methodology. In the next chapter I will introduce my participants.

The participants and their zines

In this chapter I introduce the participants and their zines. All participants have chosen whether they want to be named and whether they want their zines to be named. If they preferred a pseudonym, this was chosen by the participant and where descriptions of zines are used instead of referring to the title of the zines, the description has been written by, or agreed with, the participant. I also offered participants the opportunity to introduce themselves. If they chose this option, they are introduced here in their own words. Images of participants' zines are only included where participants gave express permission for them to be included.

Stage one participants

This section introduces the participants from stage one. I include the information they asked me to use to introduce them and some additional details from the interviews to help orient readers (e.g. the topics of their zines and where they share them). Participants in this stage are all women or non-binary survivors of the mental health system who have made zines about mental health. They all live in the UK apart from *Kira DeSomma* and *Reflective Zine* who both live in the USA. I include a list of the publicly available zines participants spoke about during the interview and the zines they shared with me as part of the interview or chose to send to me before or after the interview. These were the zines I included as data.

Tamsin

I am a white lesbian survivor of the MH system. I'm in my mid-40s. My zines that are included as part of the data (listed below) are all about experiences of distress/madness or the MH system. I have also made zines as part of a reflective process during this research, the zines where I reflect on my own experience are not listed below but are also part of the data and I also made

zines that were purely a process of gathering and interpreting info from interviews, these are not part of the data.

Tamsin has shared her zines at MH survivor activist events, at zine fairs, and with friends online and in person. More recently she has also shared her zines with MadZine colleagues and the Wellcome Library zine collection.

Zines

- *Conversations with mental health workers* zine (about inconsistency in support)
- *Self-harm alternatives* (about how sometimes self-harm is preferable to alternatives)
- *Pandemic Triggers* (about why the pandemic impacted mental health)
- *Not my shame* (Walker, 2016)²³ (about trauma and services responses)
- *Dissociation* (about the experience of dissociation)
- *Dissociation is a superpower* (about how dissociation can be useful)
- *Survivors' voices* (about how services need to change how they listen)
- *Asylum at Highroyds* (about experiences of High Royds hospital)

Rosie

Rosie describes herself as a *white British heterosexual cisgender disabled woman who has a diagnosis of borderline personality disorder*". She described her zines in the following way:

"The main themes of my zines are silence vs speaking, hiding vs visibility, disconnection and connection. The rebellious history of this expressive form makes me feel like my topics are welcome. Paper is something that makes me happy. I love how it folds, and crumples and softens beneath my fingers. Zines don't have to be perfect and that makes them liberating."

²³ Although *Not My Shame* was made as a zine it was later published in by Singing Dragon as a book (Walker, 2016).

She has sent her zines to people who bought drawings that she made, and she has shared her zines with friends. She has also shared photos of her zines on her blog although she says her zines are more personal than her blog and so not as widely shared.

Rosie's zines

- *Some people hurt themselves* (about why people self-harm)
- *Silence is not golden* (about being silenced, speaking out and problems with time-to-talk)

Annie Pocalypse

Annie Pocalypse is a pseudonym. Annie introduces herself as follows:

"I'm Annie Pocalypse. I was born in Northern France in 1986. My self-worth was destroyed by psychiatry and capitalist comp-het between 2002 and 2005. I moved to the UK in 2007, where I worked on rebuilding myself via both selfish and collective routes. My experiences of having no higher education, being a migrant, having an addiction issue alongside a stigmatised BPD diagnosis, and being a gender non-conforming woman and a lesbian, have informed most of my zines."

Annie's zines are about her personal experiences, and topics include addiction, traumatising mental health services, surviving suicide, BPD and homophobia.

Annie sells her zines on Etsy, tables them at zine fairs and has swapped zines through a zine swapping group on Discord.

Annie's zines

- *Psych Trauma* (about trauma and mental health services)
- *Good Patient* (about addiction, mental health and addiction services)

Luna Tic

Luna Tic is a pseudonym. Luna introduces herself as follows: "I'm 33. I identify as Mad and Disabled. I live in South Wales with my Mad Dog (legal term is Mental Health Disability Impairment, MHDI, Assistance Dog, or sometimes called a 'psychiatric assistance dog')."

"I make zines about my experience of Madness, Mad Activism and the mental health system from a UK/Mad Pride perspective. I find satire a helpful mechanism to break down barriers, communicate to wider audiences and, if all else fails, to make myself laugh. Topics have included my experiences of statutory services, mental health aphorisms, an introduction to Mad activism, and a zine about mental health services during lockdown."

"Where my zines contain information that could be a useful resource to other Mad/Disabled community, I try to make [them] available for free, such as through digital downloads or through acquiring private funding to cover a print run and postage for people to claim²⁴. I also use targeted drops, leaving zines in places that they will have potential impact, such as mental health service drop ins. On the rare occasion I have sold a zine via Instagram/Etsy."

Luna's Zines

- Zine about experiences of services and mental health aphorisms
- Zine guide to MH survivor activism
- Zine about difficulties accessing help during lockdown

Lisa

Lisa is a pseudonym. She described herself in the following way:

"29, female (she/her), bisexual and married (to a man), I have a history of bulimia and depression, but I am doing really great right now and haven't had any mental health concerns for a couple of years, I have endometriosis, a chronic illness that results in severe periodic pain for

²⁴ For example, Luna put a PDF of her zine about accessing help in a mental health crisis online for people who might find it helpful to download.

me. I work full time as a scientist and I am generally an introverted person who likes spending time alone, with books, with nature and with animals."

Lisa described her zines as covering depression, sexuality, houseplants, bulimia, hobbies, politics, and her physical health problems. She sells and swap zines at zine fairs, has contacted people online to swap zines and sells her zines on Etsy.

Zines

- A zine about having mental health crisis whilst doing a PhD

Mary Barba

"My name is Mary Barba. I am 30 years old; my pronouns are she/they. I am pansexual and engaged. I am white and live in the USA. I am diagnosed with PTSD and OCD, and I have recurring slipped discs in my back. I am a private music educator and performing classical musician.

Under the pseudonym Reflective Zines, I create informational zines about mental health and poetry zines. Thematically, my zines explore the feelingful experiences of being a woman with a history of being abused and the growth process coming away and staying away from those environments. I sell my zines online and at zine fairs, trade with other zinesters, and donate zines to libraries, university collections, and individuals."

Mary's Zines

- *Who am I?* (Zine about identity)
- *Daddy Issues* (Zine about relationships)
- *DBT zine* (Zine about therapy)

Kira De Somma

"Kira DeSomma (she/her) is a Queer 27-year-old writer from New Jersey, USA. As a graduate of Oxford Brookes University's Creative Writing Master's program, her creative work revolves around storytelling... the most prevalent theme of her work is mental health and wellness, as her own personal struggles with mental illness have shaped her as a creator and individual. Her

experience with mental health services has been both positive and fundamentally life-changing. She has worked with the same psychiatrist for almost fifteen years, since she was a young teen, and still sees her psychologist once a month. She believes that art, poetry, and other creative outlets for processing trauma helped her more than she can ever articulate -- zines being one of the main avenues for this kind of "art therapy". Kira used to sell her zines on Etsy, but closed her shop a few years ago and now sell them primarily at poetry readings Her motto is, Joy is as profound as despair."

Zines

- *Aftertaste* (about eating disorders)

Dolly Sen

"Dolly Sen has a brain of ill-repute and is a London-born writer, filmmaker, artist and performer. She is a disabled, working class queer, interested in disability and the madness given to us by the world. She currently resides in Norwich. She/They. www.dollysen.com"

Dolly's zines are about how mental health systems shame people for being gay, older, neurodivergent, mad, in pain or a person of colour. They show how the shame belongs to the system not the people. She shares her zines via her social media accounts and links to political spaces and arts spaces.

Dolly's zines

- *Piss off with your pain you peasants* (about how health and pain management is political)
- *Creaky Karma Sutra* (a guide to sex for lesbians with arthritis)

Rin

"Rin is a nonbinary human who uses they/them pronouns. They identify as queer, disabled and mentally ill. They are white and moved to the UK in their early 20s."

Rin's zines are about identity, receiving a late autism diagnosis, being queer, being non monogamous, gender, problems with mindfulness practices, experiences of schooling, and being an activist.

Rin has shared zines by putting them on Tumblr for people to download, tabling at zine fairs and via an online shop. They have also sent some to libraries when they have asked for zine contributions, and they left copies of one zine around their university.

Rin's zines

- *Shitfulness* (critique of mindfulness)
- *How to be an acceptable autistic activist* (about how unaccepting some neurotypical allies can be)

LJ

"I'm a 30-year-old, middle class, white, queer, non-binary person raised in the East of England but living in Scotland. I use they/them pronouns. I'm neurodivergent, and I was mad for a while because of living in a world not designed for how my brain works, and a psychiatric survivor."

LJ's personal zines include experiences of psych hospital, loss, psychosis and madness and services more widely. They have also made collaborative zines, the topics of which vary depending on who they are collaborating with.

They have shared zines via, zine fairs and social media connections as well as sending them to friends. They don't share their personal zines as widely as their collaborative zines and they choose to share in specific zine fairs where they feel part of the community.

LJ's zines

- *Psychosis Summer 2012* (about an experience of psychosis)
- *Shadow Song* (about memories of people from psych hospital)
- *Mad Tarot* (about experiences of madness and services)

Kirsty Rowles

"Kirsty Rowles is a feminist, fangirl, lesbian and Professional Nice Person (i.e. charity sector worker), in her mid-thirties and living in Swansea. She was one of the organisers of Swansea Zine Fest which ran between 2018 and 2021, and she makes the perzine Forever Incomplete about fandom, mental health, gay stuff and trying to be an adult. You can find her zines on Etsy - Forever Incomplete"

Kirsty was treated by CAMHS as a teenager and has been in and out of therapy through the NHS and private services since then.

Kirsty's readers are people who buy her zine at zine fairs, who buy from zines distros and her online shop, and friends.

Kirsty's zines

- *The common cold* (about comparing mental health difficulties to having a cold)

Stage two participants

In this section I introduce the participants from stage two. Like the participants in stage one, I include introductions the participants asked me to use and include additional details from the interviews where these details weren't included by the participant in their introduction. These details include participants' experiences of mental health services and support, experiences of what might be called epistemic injustice, where they made their zines, what their zine was about and who they shared them with. I haven't listed information about their zines separately as they described their own zines within their introductions and other than Bex their zines were untitled.

Bex

"I'm Bex and I'm a neurodivergent artist with a long and complicated history of trying to get help with my mental health. In 2020 I'd had a course of psychotherapy, and shortly after being discharged I found out that my therapist had died. It was a very difficult and isolating experience because I didn't know anyone who had been through the same thing."

My zine was a way to collect and express the feelings I'd had at that time - things I couldn't talk about and didn't feel that I could share with anyone. I'd never made a zine before, but I was aware of the concept, and it appealed to me as a way to communicate without needing to speak. And because zines are entirely self-made, there's a freedom to express yourself outside of the usual standards of editing and publishing. In the end, my "zine" evolved into something else: I added hidden pockets and secret messages, and chained it shut. In the end, it was something unique and impossible to reproduce - arguably not a zine at all, but a physical representation of isolation and the feelings I'd kept hidden."

Bex's zine was titled *Well what the fuck am I meant to do now?* Bex attended zine-making sessions with Nicola, which were held in the space where the support group she attended normally took place. Bex shared her zine with Nicola and me during and at the end of the zine-making workshops. She also shared it with Diane and Kaz at the zine sharing session held in the same venue. She also shared it with a colleague and with a group of people who were hoping to put on an exhibition about mental health and using art to externalise experience.

Diane

"Diane is a care leaver with a long history of accessing support from voluntary sector and statutory mental health services. She has found that psychiatrists don't always listen to what she says or what she would like to happen, but in the voluntary sector her comments are much more welcomed.

Diane has found that there isn't really anywhere to talk about experiences of being in care, so her zine is about care for children and young people. Diane's zine challenges the negative assumptions she's found people make about care leavers and being in care. Her zine asks people to care for and have aspirations for children who have nobody to care for them. She hadn't heard of zines before and enjoyed the process of making her zine."

Diane attended zine-making sessions with Kaz, which were held in the space where the support group she attended normally took place. Diane shared her zine with Kaz and me during the zine-

making workshops and with Bex and Nicola via the zine sharing session, which took part at a venue that was unfamiliar to her. She didn't share her zine with anyone else as she didn't feel people would be interested or value it.

Nicola

"I'm Nicola, I'm 37 and was first introduced to zines by Tamsin whilst I was attending an art for wellbeing group. I've struggled with my mental health since having to finish work due to my disability. My zine is based on raising awareness of my diagnosis of a rare autoimmune disease. Making the zine really helped me process the changes to my health and lifestyle and gave me something positive to focus on. I love how individual zines can be, thank you for introducing them to me."

Nicola attended zine-making sessions with Bex, which were held in the space where the support group she attended normally took place. Nicola shared her zine with Bex and me during the zine-making workshops and with Diane and Kaz via the zine sharing session, which took part in the same venue. She planned to share it with people in her life, including her partner, family and friends.

Kaz

"Kaz is a working-class queer queen. She's had mental health support from her local women's centre for 14 years and sometimes attends four times a week. She hadn't heard of zines before taking part in this research. She enjoyed making and sharing her zine. Kaz has experienced and continues to experience homophobia from family, friends and in her workplace. Kaz's zine is about homophobia and her experience of coming out."

Kaz attended zine-making sessions with Diane, which were held in the space where the support group she attended normally took place. Kaz shared her zine with Diane and me during the zine-making workshops and with Bex and Nicola via the zine sharing session, which took part in a

venue that was unfamiliar to her. As well as sharing her zine with other participants, Kaz shared her zine with a friend and a colleague.

Nazrah

Nazrah is a pseudonym. She describes herself as follows:

“Nazrah is a disabled woman with Jewish and Arab heritage living in the UK. She accesses a mental health support group for Asian women in Calderdale. She enjoys expressing herself in pictures rather than words and likes to communicate through drawings because people don’t have to speak the same language to understand a picture. Nazrah hadn’t heard of zines before hearing about this project. Nazrah’s zine is about the impact of covid and the social and mental health impact of govt restrictions.”

At her request Nazrah attended a single zine-making workshop in which there was only me and her in the room. Nazrah asked for this in part because she was anxious about catching Covid if she met with a group. This zine-making workshop was held in a room of the voluntary sector organisation Nazrah attended for support. Nazrah chose to only share her zine with me because she was fearful that if other people read her concerns, they might think she is “nutty” or a “crank”, this was because she felt that anyone who shared concerns about the impact of govt restrictions would be perceived in this way.

This chapter has introduced the participants, their zines and how, where and with whom their zines were shared. In the next chapter I outline how and why survivors used the creative, crafty qualities of zine-making to reflect on and articulate experiences.

Creative and crafty sensemaking

In this chapter I focus on how and why different survivors use zines and zine-making to develop and articulate survivor knowledge. In other words, I explore zine-making as an interpretive process/resource.

This chapter provides an overview of how survivors described zine-making as enabling reflection and expression of their experiences. It draws on my interviews with survivors who were experienced zinesters and the zines they shared with me; my interviews with the survivors I introduced to zine-making and the zines they made and shared during my research; and my own experience of creating and sharing zines. I couldn't identify any significant differences between how participants from stage one and stage two described zine-making as enabling their process of reflection and articulation.

The chapter will discuss, in turn, the value of zine-making as a creative visual process; the benefits of zine-making as a handmade creative process; and zines as containers.

Zine-making as a creative visual process

Survivors highlighted how zine-making can be a creative and visual process, and zines can be a creative and visual medium. When making zines, survivors use a variety of creative and visual methods to reflect on and articulate their experiences and then share this as a form of knowledge. Some survivors said that being able to use images made the process of reflection easier or more accessible because it suited how they think and some linked being able to use a creative visual process to being able to reflect on and articulate emotions or internal experiences.

Experienced zinesters Lisa, Annie, LJ, Luna, Kirsty and Dolly told me that being able to use images and visual articulation²⁵ was important to them and was their preferred method of reflection and articulation. As such they often used images to create their zines. For example, when Annie compared her experiences of drawing with her experiences of writing, she said:

“I like drawing a lot more ...drawing feels like it helps you not fit into that...stereotype or this particular box... in drawing, there's a lot more freedom ...it just feels a lot safer... With drawing you just you just draw it. Or collage.... It's a lot more straightforward and accessible in a way”

Of the survivors I introduced to zine-making Bex, Nazrah and Nicola said it was important to be able to use images in their zines. For example, Nicola said:

“I enjoy being creative. If I can draw and use pictures it makes it easier to say what I want to say”

Nazrah prioritised articulating herself via images and spent much more time, energy and space on this than using text when she made her zine. Bex said she always needed to begin by drawing things before she could articulate them in other ways and making her zine allowed her to do this. Similarly, Lisa said she couldn't think of a zine where she hadn't begun with drawing. Likewise, if I have the option I will always reflect and articulate myself visually and zines allow me to do this. If I am not able to use images, I feel like I am trying to think in an unfamiliar language.

I see the ability to choose visual articulation this way:

²⁵ Visual articulation includes images and other forms of visual expression e.g. doodles, use of line, shape, colour and texture.

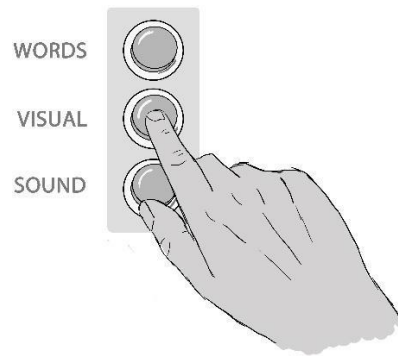


Image 5.1 Choosing visual articulation

Although just over half of the participants highlighted that being able to use visual methods made the process of articulation easier or more accessible for them, it is significant. Anything that helps people to reflect and articulate themselves might be considered an interpretive resource and this may be important for epistemic justice. It is also significant because as outlined in my literature review, as survivors we may be more likely to think visually and so to benefit from visual processes like this.

Some survivors said it was helpful to be able to articulate their thoughts visually because they think visually. For example, LJ spoke about “processing thought through image” and said:

“I draw ... because for me it's a way of like giving shape to things and because you know like I'm quite a visual person, so it makes sense to put things down on the page.”

Similarly, Lisa used pictures: “to help me think” and said, “I’ve always used doodling and drawing to express my inner thoughts”.

Lisa, LJ, Bex, and Nazrah all said they found it difficult to reflect on and articulate their experiences without being able to use images. For example, Bex said she felt more comfortable using creative methods:

“it’s how I think, I need to be able to draw it then maybe I can write about it too”

Nazrah said that because she felt more comfortable using images, she was better able and more confident to reflect on and articulate things she would struggle to otherwise: *“if I put it in pictures, I can think about it”*.



Image 5.2 Visual articulation suits how some survivors think

Like LJ, Bex, Lisa and Nazrah I think visually and so I find it easier to articulate my understandings using images. Like Lisa, I have processed and articulated my thoughts visually for as long as I can remember, and this is what I am most comfortable and confident doing. I find using images especially important when I need to reflect on and articulate complex ideas and experiences because creating images is the process through which I clarify or arrive at my understanding. For Fricker (2007), people solidify concepts through describing and then naming them and these can then be used as hermeneutic resources. However, for me ideas/concepts (as well as emotional experiences) are solidified and clarified through the process of making an image. It is a process of describing an idea in my own language. Once a concept had been captured visually, I can then use it to make sense of my own experiences (or, in the case illustrated below, to make sense of survivors' experiences more generally). If I don't create an image, the concept/theory remains amorphous to me and, therefore, unusable. All the ideas in this thesis were visualised in my head and/or drawn on paper before I attempted to try and put

them into words. Similarly, when I made zines about epistemic injustice I began by visualizing and drawing my understanding. I drew theories I had read about as a way to understand them or to see how they might work in practice. See image 5.3 below for an illustration of this process of reflection and articulation. Sometimes, as in the case below, creating the image was a way to bring together multiple theories and relate them to a particular context (in this case to survivors in the mental health system).

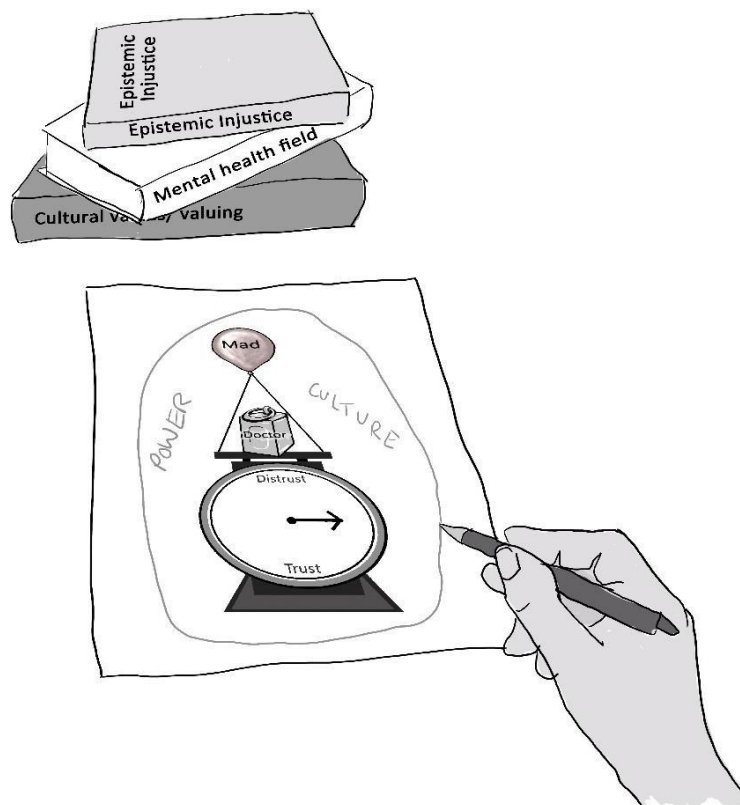


Image 5.3 Reflecting on ideas about testimonial injustice and fields of production, and thinking about how they might apply to survivors

Being able to use images when making zines helped some survivors reflect on and articulate their emotions, inner life and dissociated experiences and beliefs. Lisa, Bex and I all struggle to find words for feelings and find that if we can use images, we can more easily articulate our emotions and experiences. Lisa described images as enabling her to reflect on and articulate the experience of being depressed. She said:

“As a depressed teenager, I drew certain pictures again and again and again in all my schoolbooks – girls hugging their knees to their chest – all these little sad girls hugging their knees to their chest. It wasn’t until I was older, I thought, “oh yeah I was trying to tell people how unhappy I was, and I just didn’t have the language”.”

Lisa drew pictures and then expanded on these to create her zine about what she referred to as the worst year of her life (see images 5.4 and 5.5).



Image 5.4 Image from Lisa’s zine

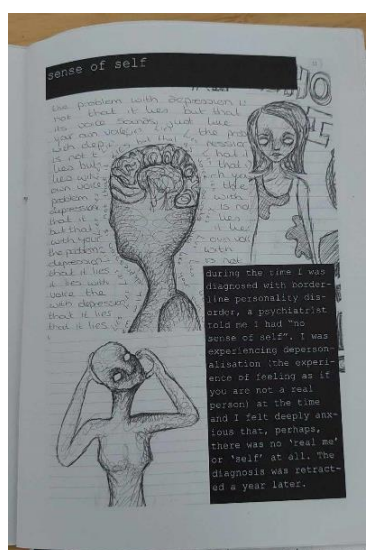


Image 5.5 Page from Lisa’s zine

Bex said that she found it really difficult to find words for emotions. She explained that she created lots of images and used lots of other form of visual articulation when making her zine because this enabled her to reflect on and articulate emotions about the death of her therapist which she would have been unable to do otherwise. Bex said

“it really helps me being able to draw and use pictures... I wouldn’t have been able to say all this otherwise... I need to be able to use colours, different types of line and textures”

See images 5.6, 5.7 and 5.8 for some examples of this.



Image 5.6 Bex's zine



Image 5.7 Bex's zine



Image 5.8 Bex's zin

Like Lisa and Bex I find it important to be able to use images when trying to reflect on and articulate emotions and experiences. It feels much easier for me to draw these or represent them visually than it would to put them into words. When I use images instead of words, my emotional experiences are better represented. I see them more clearly and I understand them better (for example see images 5.9, 5.10, 5.11). It also helps me imagine and understand other people's emotional experiences (see images 5.12, 5.13 and 5.14 for examples of this).



Image 5.9 Untitled

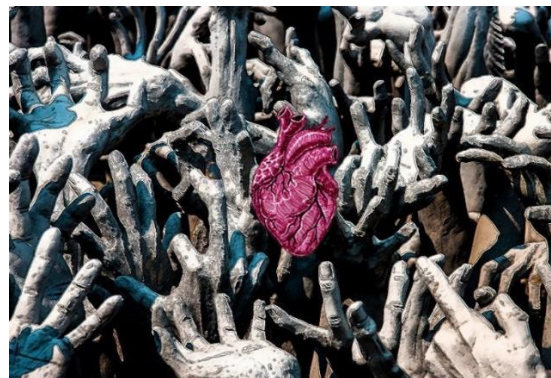


Image 5.10 Untitled



Image 5.11 Untitled



Image 5.12 Untitled



Image 5.13 Untitled



Image 5.14

For survivors like Lisa and I it wasn't just that being able to use images enabled us to articulate emotional experiences we struggled to find words for. It was more that the process of making

images made us aware of experiences that we wouldn't otherwise have been fully conscious of, let alone able to reflect on and articulate. Lisa said she often worked out how she felt by paying attention to what she was doing, and she related this to her drawing, essentially suggesting that she brought emotions into her awareness through drawing them.

This might be about bringing emotions into awareness but, more than this, it can be a process through which I become aware of dissociated beliefs and memories in such a way that I can then reflect on them. Being able to use images is like a bridge between things we struggle to be conscious of and things we can share with others. I see it like this:



Image 5.15 Bringing to awareness visually

Bex and Lisa highlighted the importance for them of being able to use both words and images when making zines, as images gave them access to emotions and words helped them to make sense of these. In other words, images were important for the first stage of reflection (i.e. capturing an emotional experience) and words were important for the second stage (i.e. interpreting the experience). Bex said whilst she captured feelings and experiences through drawing them, she worked out her thoughts through writing. Lisa said:

“I draw first, and it helps me move from feelings into words. It’s like a middle step between feelings and words”.

This is a little different from my process because, although I can find it is useful to use words to help readers understand my pictures, the words themselves don’t add to my understanding. The words are not how I interpret an experience they are only how I try to communicate my interpretation to others. Indeed, sometimes when I add words, I feel the words detract from my understanding. I feel I’m trying to translate my thoughts into a language that doesn’t work. Despite this, for all three of us, being able to use images when we make zines enables us to become aware of, identify and articulate emotional and internal experiences which we can then further reflect on and interpret.

The creative reflective methods that Bex, Lisa and I use might be described as phenomenological, in that instead of drawing on preconceived notions and assumptions (about depression or grief for example) we focus on describing the essence of the subjective experience. It has been argued that a phenomenological approach is important for survivors addressing hermeneutic injustice (Carel, 2012; Ritunnano, 2022; Parnas *et al.* 2013; Jackson, 2017) and creative and sensual sensemaking processes have been written about as phenomenological approaches to understanding experiences of illness (Carel and Kidd, 2014).

Zine-making as a handmade creative process

The survivors revealed how the handmade process of zine-making was particularly valuable to them. All the survivors I spoke to chose to make some or all their zines entirely or partly by hand. Experienced survivor zinesters Luna, Annie, Kirsty and LJ said it was important to them that the process of making zines was at least, in part, a physical process as opposed to being entirely digital.

Handmade zine-making processes included: drawing or writing, collaging pages, assembling and binding zines. In some cases, this involved using a variety of materials, adding objects to

their zines and creating zines with unusual physical structures. For example, Annie had scanned bits of plants into her Psych Trauma zine, used photographs and stickers, and wrapped and bound bits of her zine with thread and multi coloured wool. Rin spoke about having sewn elements of a zine they had made and Bex, Kaz, Diane and Nicola also used various materials and different colours and textures of paper. Nicola used paint, pens, crayons and images and words that she had printed out, Diane used felt tips, glitter, and images printed out from the internet, and Kaz used pen, crayon, images printed out from the internet, bits she had cut out of leaflets and some shiny pink foil. Bex used the widest range of materials. To make her zine, Bex used different types of paint, pen, and crayon, earth from a plant that had died, masking tape, different types of paper, scent, copies of letters from a mental health service, embroidery threads, leaves, a bandage, a chain and a stopped clock, transparent ink and staples, she also included torn fragments and tore pages in half. These choices were all part of their process of reflecting on and articulating experiences. For example, by using earth from a plant that had died; copies of letters from a mental health service; and tearing up pages, Bex was able to reflect on and articulate experiences such as absence/death; MH services formal processes/communication (i.e. the way in which services let her know about the death of her therapist); anger/frustration).

Some zinesters linked making zines by hand to being able to reflect on and articulate experiences of madness, and topics that are messy, chaotic or wild. For LJ, making their zines by hand slowed down the process of articulation which gave them more focused time to reflect on their experiences of madness (and mental health services) that they wanted to include in their zines. For Kira, Nicola and me the analogue aspect of making zines by hand helped us reflect on and articulate experiences that might not conform to/fit into a digital format. Kira said analogue methods of articulation lend themselves to particular topics and she linked this with texts made in this way feeling “*wild*” and “*overgrown*”, which is how madness can be experienced. Nicola linked being able to make her zine by hand with a sense of freedom for

example, she said that having the freedom to use different coloured paper for each page and being able to cut each one into a different shape meant she could represent how “*chaotic*” her brain was.

Like Kira and Nicola, I get a sense of freedom from being able to make zines by hand. I feel like I can articulate and share things in a handmade medium that I wouldn’t be able to if I were trying to make a digital zine or a blog on a website, or if I were filling in an online feedback form, survey or questionnaire. This is about what it is possible to articulate not being predetermined by the technology, or the way technology has been set up. For example, when making a zine by hand you don’t have to contend with preset margins or place text at right angles, and the zine itself doesn’t even have to conform to a particular shape. Making things by hand allows me to me to articulate all kinds of messy experiences, including experiences of madness and joy, neither of which are neat, binary or tame and both of which I find difficult to articulate without a handmade element. I see the analogue quality of zine-making like this:



Image 5.16 Analogue

Most survivor said they enjoyed making zines and related this to their use of creative, handmade and analogue methods, including visual and sculptural articulation and a range of materials.

Rin, Rosie, Kirsty, and Kaz spoke about their enjoyment of creating zines by hand. Kira and Dolly spoke about their enjoyment of creative processes and Nicola, Diane Annie and Bex related

their enjoyment to both the creative quality of zine-making and their handmade quality. Rosie, Diane and Annie linked making zines by hand to happy childhood memories; Rosie said handmaking zines reminded her of craft activities she had enjoyed as a child, Diane said the process reminded her of craft activities she enjoyed doing in school as a child and Annie said she enjoyed the process of making her zines by hand and was reminded of her enjoyment of making DIY media for a friend as a young person. Rosie and Kirsty said that handmade/analogue methods didn't remind them of, or feel like, work, whilst digital processes of articulation did. Kira spoke about having fun collaging images for a zine, Dolly described art as "*empowering and uplifting*", Annie said she enjoys art and having "*crafty*" zine-making processes, Nicola said that being able to combine words, images, colours and shapes made the process of making the zine enjoyable, Diane said she enjoys having time and space to think creatively, and Bex said that she enjoyed being creative and using creative methods to reflect on and articulate experiences. I also use creative and handmade methods because I enjoy using them. One survivor (Annie) specifically said she used creative methods because she associated them not having to conform/achieve.

Some survivors (like Nicola, Bex and I) explicitly linked their enjoyment of creative methods to being able to reflect on and articulate experiences that were linked with difficult emotions. For example, Bex said that her enjoyment of drawing, painting and assembling her zine by hand enabled her to reflect on and articulate the difficult and emotional experience of finding out that her therapist had died. She also spoke about her enjoyment of creativity as providing a distraction and counterbalance to her resulting feelings of grief and anger. Bex's enjoyment of the embodied creativity provided some relief from focusing on difficult experiences which meant that when she was making her zine the process of reflection wasn't entirely about the painful experience. In other words, her enjoyment stopped the process from becoming too overwhelming and enabled her to reflect on and articulate the experience. Similarly, Nicola said that her enjoyment of the creativity of zine-making made it easier for her to reflect on and

articulate the difficult experience of becoming physically disabled, because it created an alternative focus and distraction when this was needed.



Image 5.17 Enjoyment

I also enjoy being creative and the pleasure I get from mixing paints, drawing, filling and shading images can provide a break or distraction from difficult emotions when I am reflecting on experiences, beliefs or ideas that are linked with emotions that I find difficult. My enjoyment of creating zines by hand and the way that this process draws my attention to the here and now and absorbs me, enables me to reflect on and articulate difficult emotional experiences, preventing me from becoming overwhelmed by them. For me being creative with my hands is an activity I find comforting and absorbing. It is also an activity which can ground me in the sense that it can bring my awareness into my body in the present. It is an activity I can use to elicit positive feelings and sensations, including a sense of confidence. Moving back and forth between the process of creating a zine by hand and difficult experiences I want to reflect on and articulate is very much like the process Levine has called pendulation (Levine, 2010). Pendulation involves people moving backwards and forwards between fearful memories and

hopeful or joyful memories in order to make a therapeutic process manageable and not retraumatising (Levine, 2010). There is plenty of research about survivors using creative methods to make sense of experience in therapeutic settings (Sherry, 2013; Ford *et al.*, 2021; Echard, 2019) and literature linking community arts to pedagogy (Ebert *et al.*, 2015) and therapeutic outcomes (Peters *et al.*, 2024). However, little has been written about how survivors use of creative methods to make sense of experiences outside therapeutic settings might be a way to address epistemic injustice. I am not suggesting that making zines is therapeutic (although it might be). I am arguing that enjoyment of zine-making can help manage emotional activation and so enable survivors to reflect on and articulate difficult emotions and experiences. This enables some survivors to reflect on and articulate experiences that we wouldn't be able to otherwise. In this way you might describe the enjoyment of the zine-making process as an epistemic resource.

Zines as containers

In this section I write about zines as containers and suggest they can help contain (personal and emotional) content and the process of reflection and articulation. Bannister (2020) has written about comics in box form and suggested the box structure serves as a container; and in June 2021 students from the Royal College of Art created artists books for a publication project they called "the book is a container" (Southwark Park Galleries, 2021). In relation to art therapy there is wealth of literature about how art materials and artwork can help provide a sense of 'containment' (Proulx, 2000; Rogalski, 2023) and Clacherty (2024), writing about art therapy with young refugee adults and children, has described zines as a container in which fragments of lived experiences and memory might be gathered. However, what appears to be meant by the term containment varies. The meaning of containment in therapeutic settings has evolved, drawing on Bion's (1962) ideas about containment and the relationships between container/contained, and Winnicott's (1960) idea of a holding environment. There is a lot of debate about the similarities and differences between these ideas (e.g. Ogden, 2004; Aguayo,

2018; Abram and Hinshelwood, 2023) which I am not going to get into here. Rather, I simply use the words contain(ment/ing) to refer to the act, process or means of providing limits/boundaries which are experienced as enabling rather than constraining. They may be enabling because they provide a sense of safety or because they provide focus and prevent a task from being overwhelming. I use the word container to refer to the object which provides the containing limits. Although they did not use the words container, containment or containing, some of the survivors in my study seemed to suggest that zines functioned as what I call containers.

Some survivors use zine-making as a process of reflection and articulation because they feel it is safe(r) and manageable. This was related to the boundaries created by the (size and amount of) paper and by the limited number of copies. These boundaries help contain the reflective process and the process of sharing testimony. They don't restrict what the content can be, however, some testimony or experiences might feel too big to fit into a standard sized zine, although none of my participants found this. I see zines working as containers like this:

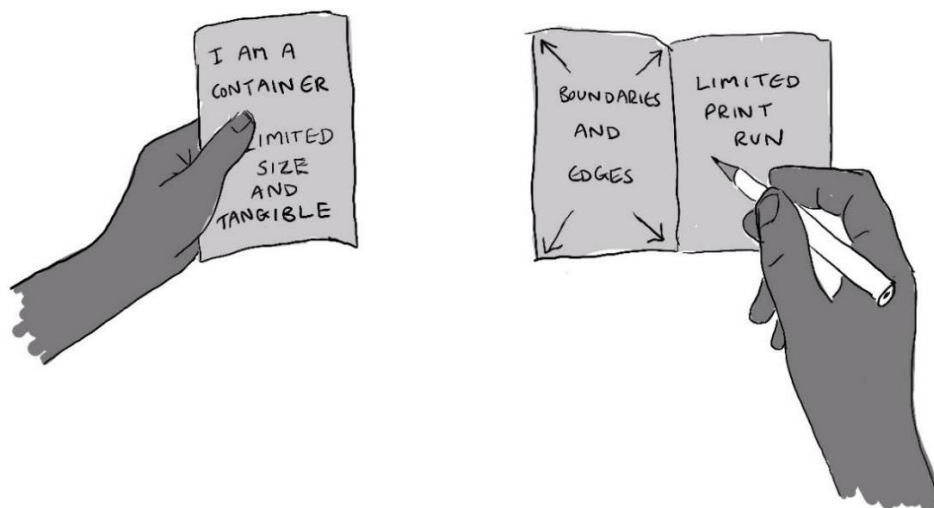


Image 5.18 Containment

Zines usually have restricted space and zine makers are usually limited by the amount and size of paper.²⁶ LJ, Rosie, Rin, Kirsty, Annie and Diane drew attention to how this meant that their zine-making involved fitting content into the boundaries of the physical space. Some survivors further said that they found that having to fitting things onto a few sheets (or one sheet) of paper was helpful because it helped the process feel less daunting or overwhelming. For example, Rin, Kirsty, Annie and Diane said that zines being a predefined physical space helped them to articulate themselves. Diane made a mini-zine using two sheets of A4 paper and said doing this made the process of making a zine feel “*less daunting*” and made it easier to decide what to say. Annie said the material quality prevented her from becoming “*overwhelmed*” by the process of makes zines about mental health and experiences of services. Rin said it gave them “*permission to condense it... [and not have to] “explain myself in a lot of detail”*”, in a zine, they said “*I don’t need to explain all the background and stuff*”. Kirsty said “*fitting something into a smaller space*” helped her articulate her thoughts on expansive topics because it meant she had to reduce the topic to its essentials and prevented her from feeling she had to say everything she could possibly say on the topic. For example, making a mini-zine enabled her to articulate her experiences of disordered eating:

“If I tried to write this long nuance about like how fatphobia and diet culture interact with peoples eating habits and how fucked up this is and it’s all nonsense anyway. I’d never do it because it’s too big”.

Essentially the paper that zines were made on created a perimeter which helped some survivors feel the process of reflection and articulation was more manageable, you might say it helped

²⁶ All the experienced zinesters and all the survivors I introduced to zine-making made all or most of their zines as physical products. Luna, Annie, Kirsty and LJ specifically highlighted the importance to them of producing a physical object as did two of the survivors I introduced to zine-making.

contain the process. It helped them focus and reflect on experiences and topics that otherwise would feel overwhelming, including experiences of madness and mental health services.²⁷



Image 5.19 Focus

Some survivors found it helpful that there were limits to how many copies there could be of a zine, how far zines could travel and how long they would last. Rin and Annie point out the longer a zine is, the fewer copies they will be able to print so zinesters must choose between sharing more content with a fewer people or less content with more people. Rosie spoke about being able to articulate more personal content in her zines as she knew they would be for a smaller audience. In contrast Rosie said that her blog is for a “*wider audience*”. She says that in her blog:

“I wouldn't go into like, personal details or names or I won't talk about my, going on holiday, or things like that. But if I wanted to, I could do that with a zine”

Rin pointed out that with digital media there are essentially no limits to how long it is available for people to read or how long you can keep editing it for. They linked this to being unable to let go of what they had written. They contrast this with their experience of zines:

²⁷ Notably zines are a flexible container; both Kaz and Bex added pages when they ran out of space and found there was more they wanted to say.

“What I found helpful about zines is that even if I read it six months later and I realize I made a typo or spelling mistake, or there's something unclear. Even if I was to rewrite the entire Zine, they're already some in the world. Whereas when I've written stuff like blog posts. Three years later, I might read a blog post and edit it.”

In a similar way to LJ, Rosie, Rin, Kirsty, Annie and Diane, I am reassured by the material boundaried qualities of zines. I am reassured that I can see and feel their edges. I am reassured that I know how many copies there are, that I can control who I share these copies with and have some control over where they end up. I find that these boundaries make it possible to articulate and share personal information and sensitive emotional experiences that I might not share in less boundaried spaces, including experiences of MH services. In contrast, testimony shared in a form that doesn't have a tangible boundary feels much less contained. There are no limits to the length/size of a digital document, there are no limits to how many people it can be shared with or how long it will be available for. Digital documents can endure indefinitely and be shared with any number of people as cyber space is essentially unlimited. For me, the physical limitations of zines help me to articulate experiences and emotions which I can be overwhelmed by in a way that feels safe(r), helps me clarify to myself what is important and can (sometimes) help me to not share things that I might later regret. If we are articulating and sharing experiences and knowledge about topics that can feel difficult to contain like madness and distress, then it can be particularly helpful to do this in a medium that works as a container. For some survivors, being able to materially contain their words, thoughts and feelings in zines was linked to them being able to share things they couldn't articulate in the presence of others. Diane said that some things were difficult to say out loud, but she could write them on paper and put them into her zine and Bex said that she couldn't access emotional experiences whilst in the company of other people but could access them at home and draw and write them into her zine. Both then shared their zines. It seemed that because zines worked as a material

container, they were able to separate the process of articulation from the process of sharing.

Like Diane and Bex I have also made and shared zines which contained things that I wouldn't have said in person and would have struggled to articulate around other people. However, once I had expressed them in a zine, the decision to share became much easier because the process of articulation had taken place. The zine held the content, and I knew what I would be sharing.

The materiality of zines helps contain the content, the reflective process and the process of sharing testimony. Participants didn't experience this as restricting what the content could be.

On the contrary the availability of a container helps some survivors to reflect on and articulate difficult personal and emotional experiences, things that are difficult to say out loud, experiences of madness and services, and topics they feel are expansive. You could describe a contained process as an interpretive resource in that some survivors said the contained quality helped them to reflect on experience and articulate their understanding.

You could argue that survivors might particularly benefit from a process which is contained and not overwhelming because we may be more likely to have difficulties concentrating or focusing. Various psych diagnoses are associated with difficulties concentrating or focusing, for example depression (Watts and Sharrock, 1985), anxiety disorders (Adwas *et al.*, 2019), and ADHD (Reaser *et al.*, 2007) as are the effects of some psychiatric medications (Stein and Strickland, 1998). You could also argue zine-making is a contained process which can act as an interpretive resource which may be particularly important to survivors because we may want and need to reflect on and articulate experiences that might otherwise feel overwhelming, for example difficult emotional experiences, experiences of madness and services.

Summary

Participants highlighted various aspects of zine-making that they found useful for reflecting on and articulating experience and different zine-making qualities were described as having different benefits. For some, the creative and visual qualities enabled them to reflect on,

articulate and then share emotional and internal experiences that we wouldn't have been able to otherwise. These qualities were also felt to be useful more generally for survivors who described themselves as visual thinkers, because they made the process of reflection and articulation easier and more accessible for them. Some survivors found the handmade qualities of their zine-making helped them to reflect on and articulate experiences like madness, which are messy, chaotic or wild. For some survivors their enjoyment of, and focus on, zine-making enabled them to reflect on and articulate difficult experiences by helping them not become overwhelmed by the associated difficult emotions. For some survivors the way in which zines contained the reflective process made it feel more accessible, manageable and less overwhelming. Some survivors found the way zines contained the content enabled them to reflect on and articulate personal and emotional experiences, and things that are difficult to say out loud.

As outlined in my literature review chapter, some survivors are more likely to think visually and some of the participants in this study highlighted how they can benefit visual processes of reflection and articulation. Therefore, whether survivors have access to visual processes of reflection and articulation might be described as a matter of epistemic in/justice. If a group of people are epistemically disadvantaged because the interpretive tools don't suit how they think then I would argue they are experiencing epistemic injustice. I would further argue they are experiencing a type of epistemic injustice that can affect their ability to articulate and share important aspects of their experience.

You could describe all the zine-making qualities identified in this chapter as interpretive resources in the sense that they are all qualities that in some way enabled survivors to reflect on and articulate their experiences. Although Fricker (2007) only focuses on conceptual resources in her account of hermeneutic injustice, Kidd and Carel (2018) describe hermeneutic resources as including "appropriate language, metaphors, and images" (p. 219) and others have also

extended the idea of what might constitute hermeneutic resources (Ferguson, 2025; Shotwell, 2017).

You might further describe the visual and creative, handmade and contained qualities of zine-making as hermeneutic resources that are part of an alternative epistemological system which is geared towards understanding subjective experience. As I established earlier, survivors are epistemically disadvantaged by the ontological and epistemological assumptions within mental health systems and might benefit from a more phenomenological and subjectivist epistemological system. I will discuss the relevance and importance of alternative epistemic systems in chapter 10

In this chapter I have outlined how and why survivors found some qualities of zine-making helped their process of reflection and articulation and enabled sense making. For some survivors the flexibility of zines' structure is particularly important for sensemaking and articulation Therefore, in the following chapter I will explore in more depth how and why some survivors used the flexible structure of zines to develop, articulate (and share) knowledge.

Structure, sensemaking and articulation

In this chapter I focus on how different survivors use the flexible structures of zines to enable non-linear sense making. I use the word structure to refer to the arrangements of and relationship between elements of a zine, or other form of testimony. As I outlined in my literature review chapters, there has been limited research about how being able to use a variety of structures might enable survivors to reflect on and articulate our experiences, in other words how structures might serve as interpretive resources.

I explained that non-linear experiencing and patterns of thinking are often seen as nonsensical and linked to a variety of psychiatric diagnoses. I further highlighted the ways in which expectations of the narrative form may make it difficult for survivors to reflect on and articulate our experiences I suggested that because some survivors are more likely to experience and think in non-linear forms we may be particularly disadvantaged by these forms of thinking and articulation being pathologised or not being perceived as valid/valued. I also suggested that, because non-linear experiencing is systematically conceptualised as pathological, it may be difficult to get non-linear sensemaking recognised and valued in the MH system. Whilst literature suggests comics and graphic media may be able to represent traumatic experiences via non-linear narrative forms, this tends to focus on graphic media as a communication medium and the experience of readers, not on whether or how being able to use a less commonly used narrative form might help survivors to develop and articulate our understanding. You might say it focuses on the testimonial exchange and not on different structures as interpretive resources/tools. In addition, the literature about non-linear structures in zines hasn't been extensively related to theories about epistemic injustice or to the multiple difficulties/barriers survivors experience when it comes to reflecting on our experiences, articulating and sharing our understandings and having these appropriately valued.

Therefore, this chapter explores how zines can provide ways for survivors to express their experiences and perspectives without the imposition of linear structure; how this non-linearity can suit survivors who experience their self or their memories as fragmented; and how non-linearity can create space for detail, complexity and surfacing the implicit. I also describe how making non-linear links can help survivors both to interpret and represent their experiences and to invite readers to participate in sensemaking.

To do this, I will draw on my interviews with experienced zinesters and the zines they shared with me; my interviews with the survivors I introduced to zine-making and the zines they made and shared during my research; and my own experience of creating and sharing zines.

Expectations and limitations of linear narratives

Findings from this study echo concerns about the limitations of linear temporally ordered narrative structures (Woods, 2011; Donnelly, 2021) and the difficulties survivors might face in finding audiences that value sensemaking that doesn't conform to these structures (Gee, 1991; Reissman, 2008; Ingram, 2016). The below image shows how I understand linear narratives.

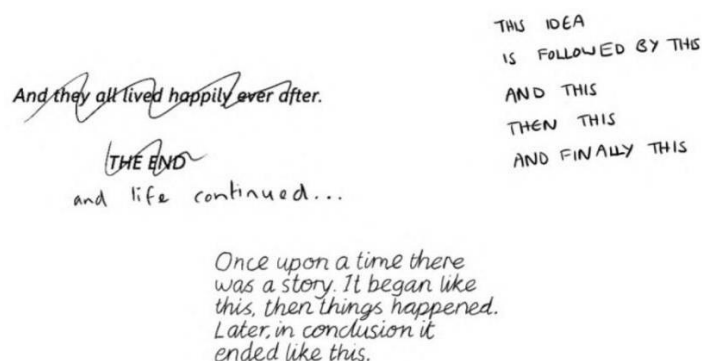


Image 6.1 Linear narratives

Some survivors described being cognisant of these linear structural expectations. For example, experienced survivor zinesters LJ and Annie both described mental health services and mental health awareness campaigns as having particular expectations of how survivor testimony should be structured. LJ described them as demanding that survivors “tell their story” and

“make it digestible”, whilst Annie said they expect survivors to create perfect linear narratives with happy endings. LJ’s and Annie’s accounts resonate with my own experiences of being asked to tell my story in services. They also resonate more widely with research that suggests that, in the West, readers expect testimony to be shared using a single unbroken linear structure held together by a plot or explicit links (Donnelly, 2021).

Some survivors internalise these cultural norms and expectations of structure and feel they need to make their testimony accessible to people who are used to linear plotted stories. LJ said they felt they had to balance the need to create something that was coherent to the person reading it with wanting to truthfully articulate experiences that didn’t conform to this structure. Likewise, I believe the difficulties I have encountered articulating non-linear experiencing relate to my having internalised the idea that accounts must be articulated in a linear temporal form. This internalisation may be related to growing up surrounded by narratives which are linear and temporal. It also came from having had non-sequential testimony corrected or restructured in educational settings, perceived to be nonsense in social settings, or perceived to be a symptom of pathology in medical settings.

Some survivors experience these testimonial structural expectations as limiting because they find it difficult to articulate and share non-sequential experiencing, memory and/or thinking using a single cohesive linear form. Experienced survivor zinesters Annie and LJ and novice zinester Bex specifically told me they found linear sequential form limiting. Annie reflected that sequential texts smoothed out important detail; LJ said they couldn’t represent how they thought or experienced things using a single linear temporally organised structure; and Bex said she found it difficult to organise her thoughts and experiences into a single cohesive linear plot. I have also found linear temporal form limiting in relation to my own forms of sensemaking especially in relation to non-linear experiences like dissociation. In a blogpost on the MadZines

website I write about how I and other survivors use zines to show the (non-linear) links we make when having experiences that might be called dissociation and psychosis (Walker, 2023).

The flexibility of zine structure

Zines have a flexible structure. This is evident through the different ways information can be ordered and linked on pages and between pages, and through the ability to change the physical structure of zines through folding and binding them in different ways, adding inserts and so on. Whilst there was a lot of variety in how participants used the flexibility of the zine structure, bar one, none of the zines the participants created had a single sequential structure or plot. Some survivors chose not to have individual pages organised according to a conventional linear temporal sequence starting at the top (left) of a page and going to the bottom (right). For example, experienced zinester Luna described arranging information on the page in a way that she felt was more aesthetically pleasing and accessible. Similarly, experienced zinester LJ, and novice zinesters Diane and Bex grouped or arranged information on some of the pages of their zines according to themes or categories, and Bex and I created diagrams or arranged elements on the page according to how they might be linked (see images 6.2 and 6.3).

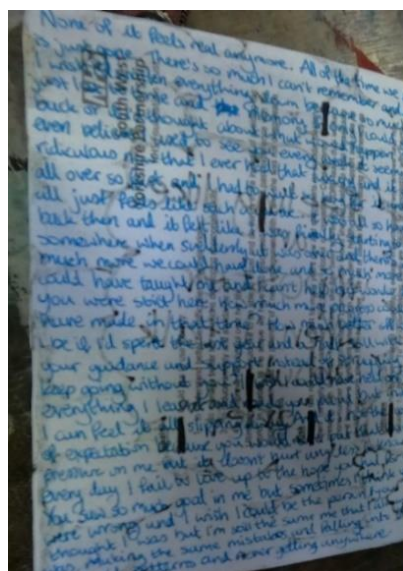


Image 6.2 page from Bex's zine



Image 6.3 page from Making (un)common sense.

Other than Rin's Shitfulness zine, none of the zines that experienced zinesters shared with me, or the zines that novice zinesters made as part of this study, had pages that were linked according to a linear temporal sequence or plot. Put another way, none of them ordered their pages to represent a single linear timeline or a sequence of causal links, or sequential argument with each page building on the previous page. For example, the pages of Bex and Diane's were loosely linked only by being in the same zine or by being broadly on the same topic. LJ's zines were linked by song lyrics; the pages of Nazrah and Rosie's zines were in the order in which ideas occurred to them; whilst the pages of Nicola's zine and half of Kaz's zine were linked though having a line on each page from a poem they had written.

Some survivors created three dimensional structures by folding and binding their zines, or by adding inserts. Experienced zinester Annie described this as the "*freedom of the zine format*". She created a zine with inserts, to contain information that could be read separately or as part of the main text (image 9). Prior to interviewing Annie, and reading her *Psych Trauma* zine, it had not occurred to me that the flexibility of the physical structure of zines could add an extra dimension to what it might be possible to articulate and share via zines.²⁸ In zines information can come off the surface of a page, it can be connected to a page without being on the page (image 6.4).

²⁸ I use the term sculptural elements to refer to elements of zines that are different or additional to the page surface. This includes how zines are folded, whether they have inserts, the shape of the paper, whether they have objects attached to them or wrapped around them.



Image 6.4 Page from Annie's Psych Trauma zine

Like Annie, novice zinester Bex created a zine with a very complex physical structure which emerged through the creative zine-making process. This included lots of sections which opened out and contained pages and inserts that were fragmented or ordered in surprising or non-standard/unusual ways. In this way, Bex used the physical construction of her zine to articulate aspects of her experience that are linked in complex and non-sequential ways.

Kaz also used the flexibility of the physical structure to make non-sequential connections. She created her zine using a concertina fold, which meant each page could be read separately or one side could be read as if a single page (image 6.5). On one side she grouped basic information about her experience of coming out (image 6.5), whilst on the other side (image 6.6 and 6.7) she grouped more detailed information into three sections: information about her sense of identity; her thoughts about and experiences of homophobia; and positive statements about coming/being out.



Image 6.5 Side 1 of Kaz's zine

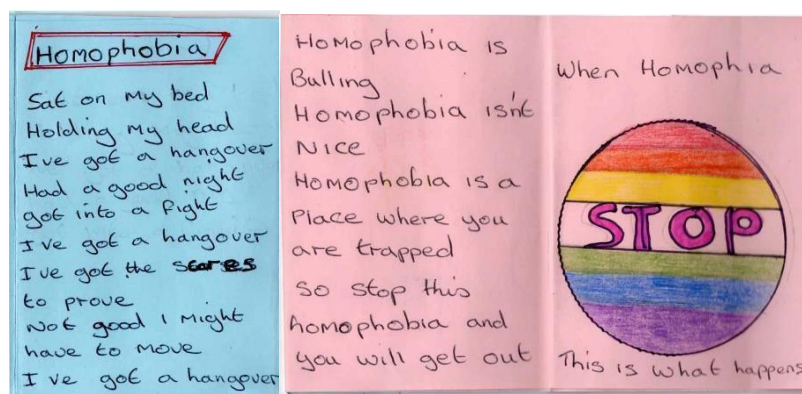


Image 6.6 Side 2 of Kaz's zine

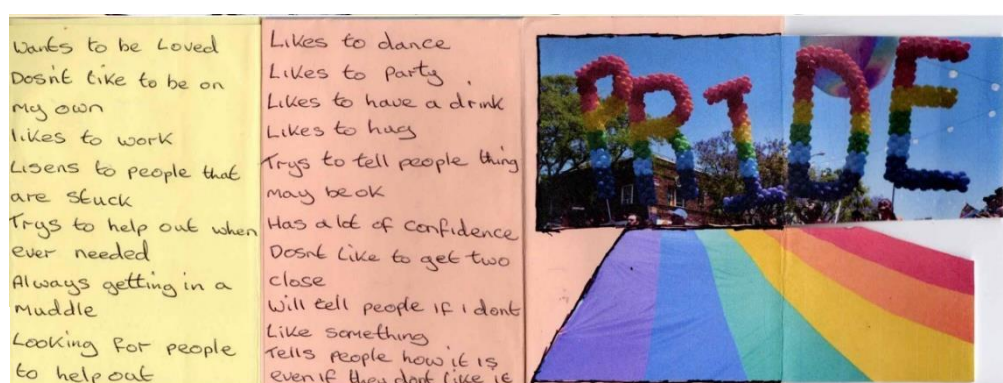


Image 6.7 Side 2 of Kaz's zine

All but two of the experienced zinesters described the structure of their zine as being able to emerge through the physical process of creating the zine instead of the process of articulation being shaped around trying to produce a particular form. None of the survivors said they felt

restricted by structural form when creating zines. LJ and Annie both favourably contrasted the flexibility of zine structure with their experience of the restrictive linear expectations of form in mental health services and mainstream mental health awareness campaigns. Like LJ and Annie my experiences of the flexibility of the zine structure contrasts favourably with my experience of services which expect survivors to share our experiences as stories, and more generally my experiences of other mediums, like essays or blogs where I have found I'm expected to have a beginning, middle and end with a linear narrative threaded through. My experience of the flexibility of zine structures is partly about the flexible, relaxed and unstructured atmosphere of zine culture and partly about the flexibility of the medium itself.

Essentially, the flexibility of zine structure gives survivors the freedom to choose whether, or how, they link different bits of information in their zines. As I outlined in my literature chapter, some survivors are more likely to think in patterns and to not experience time or self as linear, and we might need access to alternative structures in order to articulate our thinking or ways of experiencing. However, as I also outlined, it may be difficult to get non-linear articulation and sensemaking valued in the MH system as non-linear experiencing and organisation of thoughts is systematically conceptualised as pathological. I will explore this later in this thesis.

Articulating non-linear experiencing and memory

As discussed earlier, some survivors experience time, sense of self or memories as fragmented or non-linear and can find it difficult to articulate their experiences using a linear sequential structure. The flexibility of zine structure appeared to enable some survivors to reflect on and articulate these particular forms of experiencing. For example, LJ said they don't experience memories or life as linear which means they cannot share these memories authentically using a sequential structure:

"I have come to accept I will never experience my memory or my life as one continuous line. I couldn't ever tell you a story from then to now and feel like it was accurate or authentic"

LJ described putting non sequential experiencing into a sequential structure as:

"translating it into an experience that is normal and makes sense."

Instead of translating their experiences in this way, LJ used the flexibility of zine structure to create non-sequential accounts of their experiencing. LJ explained how their zines are structured around things that happened at a specific time, events which have things in common, or things which are related to a set of thoughts or feelings. In other words, the structure of LJ's zines articulates their associations and the form of their experiencing and memory. Speaking about the structure of their zines LJ related it to:

"The last time I thought about and remembered these things, or the ways that I brought these things together in my head"

In their zine *Psychosis Summer 2012*, LJ shares a string of images representing their experiencing. Instead of panels and pages ordered to suggest a single temporally ordered sequence of events, LJ uses each page and the relationship between panels to show how experiences were related for them (images 6.8, 6.9 and 6.10).



Image 6.8 LJ's *Psychosis Summer 2012* zine



Image 6.9 LJ's *Psychosis Summer 2012* zine



Image 6.10 LJ's *Psychosis Summer 2012* zine

Similarly, in their *Shadow Song* zine, LJ doesn't create a linear temporal account of their time in psychiatric hospital. Instead, the panels are non-sequential images of the hospital and grounds, and, between these, they share song lyrics which relate to their memories of being in hospital (images 6.11 and 6.12).



Image 6.11 LJ's *Shadow Song* zine



Image 6.12 LJ's *Shadow Song* zine

Like LJ, I don't always experience time or self as linear and sequential. For me, this seems to be related to trauma, because I did not experience, and cannot recall, traumatic experiences sequentially. For this reason, I am unable to articulate my non-linear experiencing using a linear sequential structure. For example, when I created *Not My Shame*, I found I was unable to articulate my experience of trauma using a linear structure because I did not experience the things I wanted to articulate as occurring in a linear form or even as happening one thing at a time or from a single perspective. I couldn't place my experiences on a timeline (image 6.3) or create a chronicle of my experiences, let alone create a plot with sequential causal links. Even if I had been able to find out from other sources in what order the events happened, and used this to create a temporal sequential account, it wouldn't have articulated the way in which I actually experienced things.

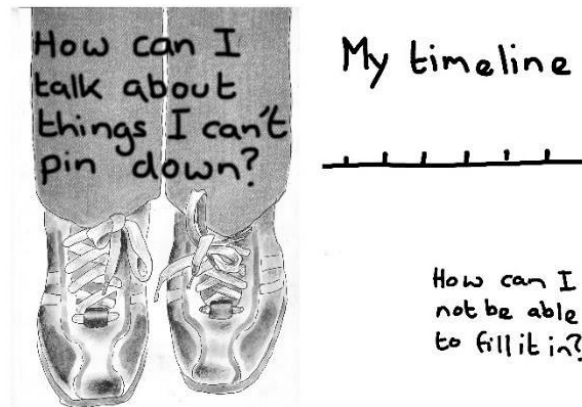


Image 6.13 two panels from *Not My Shame* page 12

It was only when I stopped trying to fit my traumatic experience into a linear structure that I found I could articulate the testimony I shared in *Not My Shame*. Like LJ, I developed a structure to represent my associations, how events were linked in my mind, and the way in which I experienced them. I used a structure that represented my experiences from inside my way of experiencing (Walker, 2023). In other words, I used a non-sequential structure to represent my non-linear experiencing of time (and self/perspective). In this way, I could articulate how I felt I moved between different moments in time, ages, places and events and sometimes experienced them in parallel or inside each other.

For example, in the panels on the following page (image 6.14) I tried to show myself remembering a traumatic experience, and then how, at the same time, I (re)experienced another earlier traumatic event and how that, in turn, reminded me of other earlier experiences. By jumbling illustrations of myself at different ages, places and times, I tried to articulate how my sense of self, way of perceiving things, and sense of time, jumped around.



Image 6.14 Panels from *Not My Shame* p. 53

By drawing some experiences in parallel I tried to show how I felt like they were occurring at the same time and within each other. The flexibility of structure made this possible, as I couldn't have articulated this using a linear structure.

Space for detail, complexity and surfacing the implicit

Another benefit of the flexible structure of zines is that it can enable survivors to articulate and share rich details and complex content that they think is relevant and make tentative or implicit links. In this way, it can enable survivors to share their knowledge-making in process.

The image below is how I understand the lack of predefined structure within zines which creates space for detail and ideas that don't fit into a single argument or story.

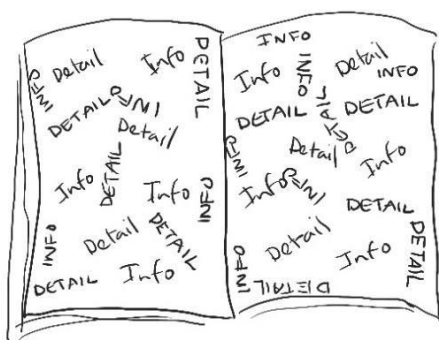


Image 6.15 Lack of structural restriction

Fitting content into a predetermined and inflexible structure can result in missing important content. Experienced zinesters Annie and LJ referred to this as linear narratives smoothing out detail; Annie described accounts that conform to linear structures as “*sanitised*” and missing the “*richness*” that can be found in zines. Similarly, LJ described them as “*two dimensional*” and suggested they don’t articulate “*complexity*”. If we have to focus on fitting our experiences into a predefined structure it may be difficult to include information which is anomalous or contradictory. Similarly, if our focus is on creating a sequential temporal structure in which each event leads to, or causes, another then we may find there is little space to articulate nontemporal relationships. For example, it makes it harder to include the social, geographical and political contexts in which events take place because information about context is not

necessary to (or the focus of) a sequential temporal structure and space may not be made for it within the structure. The result may be to decontextualise survivors' experiences, and this makes it difficult for us to understand and communicate the impact of wider circumstances. It is also significant because as I outlined earlier, there is an overreliance on diagnostic framing in the MH system and diagnoses aren't very useful for understanding the complexity of survivors' experiences and the significance of context (Shaw and Proctor, 2005; Shaw and Proctor, 2004).

The diagrams below (images 6.16 and 6.17) are how I see linear structure in comparison to non-linear structure.



Image 6.16 linear structure

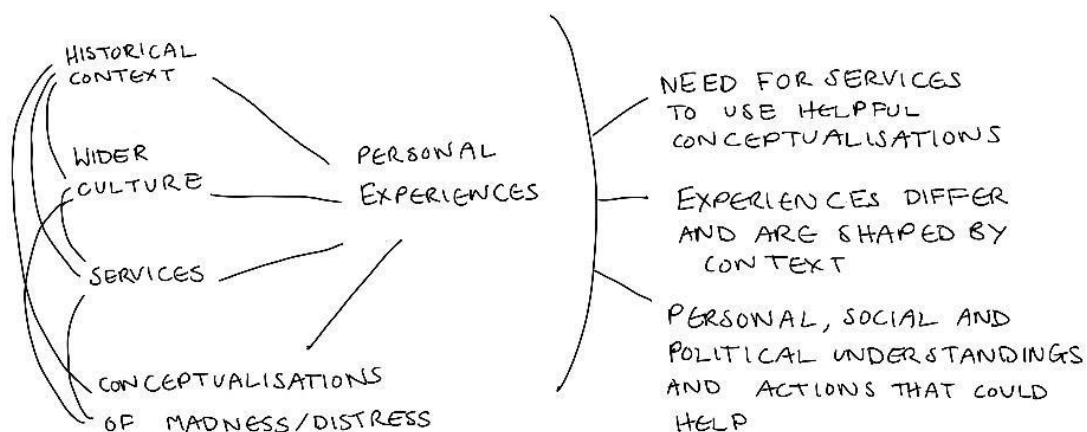


Image 6.17 Non-linear structure

Because of the flexible structure of zines, survivors can create structure to fit content instead of the other way round. Some survivors use the flexibility of zine structure to articulate and share the richly detailed descriptions and information they feel is relevant to the topic of their zine. Annie's zines for example, are very rich and full of details and descriptions which she describes as being difficult to articulate in linear structures. In her *Psych Trauma* zine, she uses the structure of the zine to create, bring together and suggest connections between various events,

ideas and experiences and contexts. For example, she connects the historical context of the medicalisation of homosexuality; the MH system relying on the medical model of madness; and inaccurate portrayals of psychiatric hospitals in the media.

The first page of Annie's *Psych Trauma* zine (image 6.18) is a block of writing which includes, in the following order: perceptions of trauma, difficulties thinking about trauma, internalised negative perceptions of homosexuality, historical medicalisation of homosexuality, the personal impact of this, ongoing pathologisation of homosexuality, the need for better approaches for dealing with trauma and finally a sentence about what trauma is and how it can impact on us.

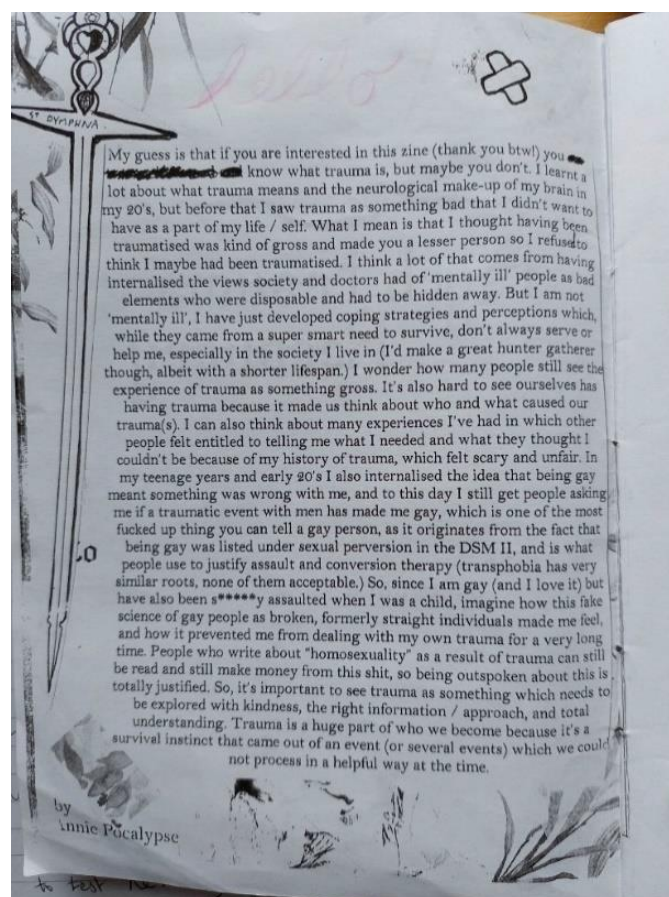


Image 6.18 Annie's *Psych Trauma* zine

The next page (image 6.19) includes an insert of a two-sided A4 sheet of writing about traumatic experiences that Annie faced in services as a child/young person. On the next page (image 6.20) is an insert of a booklet about things Annie finds useful for dealing with psych trauma.

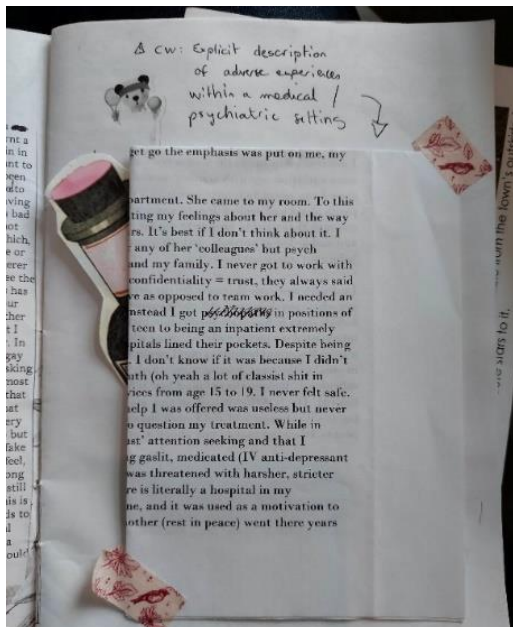


Image 6.19 Annie's Psych Trauma zine



Image 6.20 Annie's Psych Trauma zine

On the next page (image 6.21) Annie outlined how she tried to avoid the medical model, in response to earlier experiences of services, and then described her experience of a recent visit to a health centre and her observations that there are systemic problems with medical services and how hospitals are portrayed in films/media. Finally, she explained that people have differing experiences of services and psych trauma.

It would be extremely difficult, if not impossible, to include all the information included in these four pages (images 6.17, 6.18, 6.19, 6.20 and 6.21) using a single sequential structure.

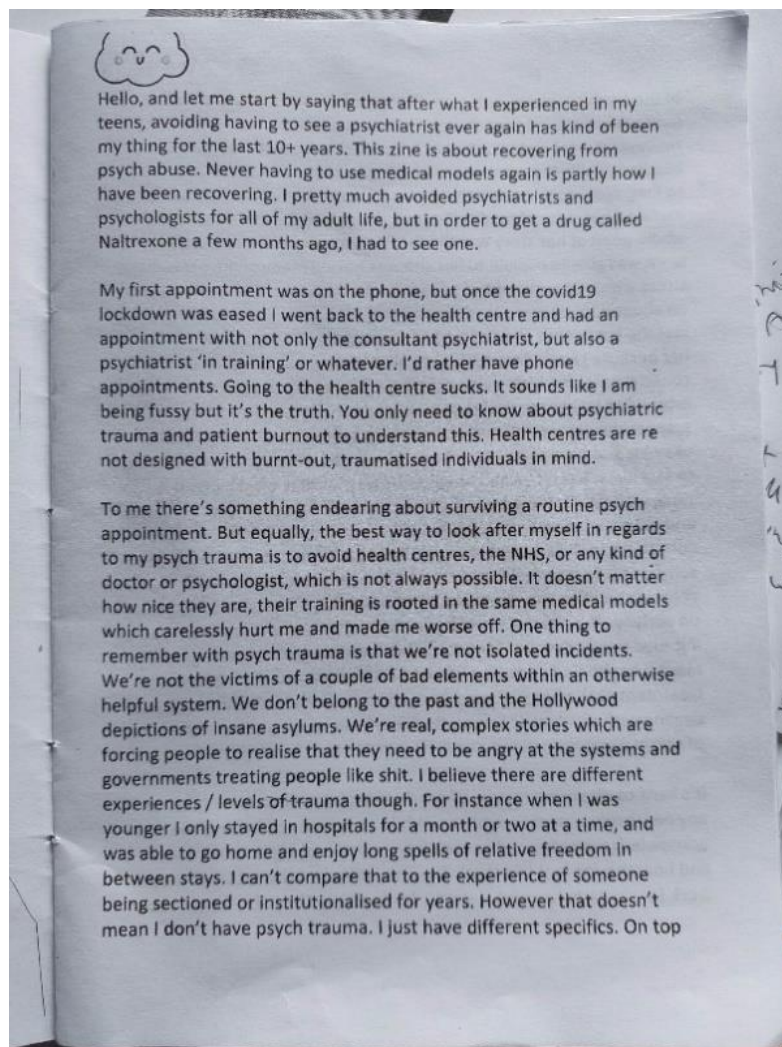


Image 6.21 Annie's Psych Trauma

Annie also used the flexibility of the structure of zines to include ideas that are not part of a single cohesive argument or story. For example, in *Psych Trauma* zine she makes an important point about the contrast between feeling apprehensive about an appointment and the experience of actually feeling triggered by an appointment (image 20). This point is not part of a single sequence, in that it isn't dependent on the information or arguments that come before it and the information and arguments that come after it don't depend on it. Whilst it isn't part of a wider understanding or interpretation, it fits within the

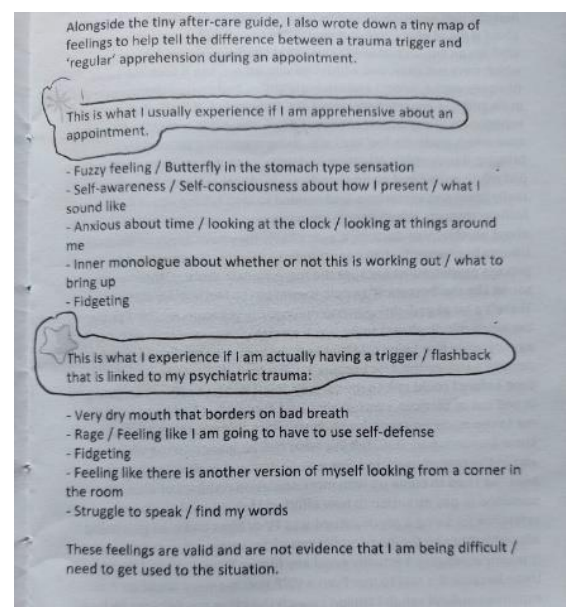


Image 6.22 excerpt from Annie's Psych Trauma zine

overall theme of the zine - the trauma she experiences in and from MH services.

Loose, tentative or implicit links

Some survivors used the flexibility of zine structures to loosely, tentatively or implicitly link content. Being able to loosely, tentatively or implicitly link content, instead of making explicit links and interpretations, may be useful if people have low epistemic confidence or if they are concerned that their interpretation may be responded to in a negative way, as well as if people are generally not sure and want to try out ideas. As I outlined earlier, some survivors have low epistemic confidence which may be related to how they are perceived and treated in the MH system and some survivors feel it is risky to share their interpretations in the MH system. Survivors may also do this because an experience is difficult (or impossible) to make sense of.

Whilst experienced zinester Luna described her zine-making as a process in which information is brought together to create an explicit message, others like novice zinesters Nazrah, Kaz, Diane and experienced zinester LJ tended to use the process to gather ideas and make tentative or implicit connections. For example, Nazrah created a zine which brought together all her concerns about Covid and lockdown, whilst Kaz used her zine to bring together information about homosexuality, the local women's centre, and her experiences of homophobia and coming out. Neither Nazrah nor Kaz explicitly made links between the different elements of their zine although, by including them in the same zine, they imply they are linked and relevant.

Similarly, Diane used her zine to gather information and loosely hold it together. In just a few pages (image 6.23), Diane brought together information about negative outcomes for children in care; the need to create better opportunities for children in care to raise their aspirations; her experience of local authority care being better than being in a family; people having negative perceptions of care leavers as parents; and challenges to these perceptions. In one place Diane suggested how one piece of information might be linked to another - by adding the word

“however” (above the third page) - at no point in the rest of her zine does she explicitly say how different elements are linked.

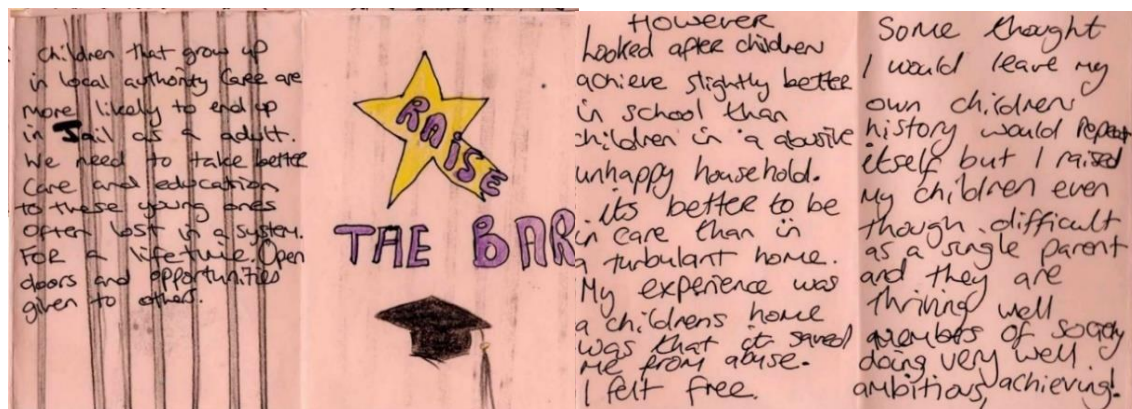


Image 6.23 Diane's zine

Explicit, contextual and/or comparative links

Some survivors used the flexibility of the zine structure to make more explicit non-sequential links which addressed wider contexts, comparisons and themes. For example, Annie made explicit the relationship between personal experience and the social and political context. Annie said that when she wants to articulate an experience, she begins with an emotion, then links this to the immediate context in which it is experienced and then the wider social and political context and that this is how her structure is created.

"It always starts from feelings, for me. It starts from feeling and the feelings really attached to the sense of place you know, and the descriptions of what's going on. It starts from feeling and then, the kind of ethics, or whatever, the politics kind of graft themselves onto it... This is multi-dimensional. It's the politics. There's time and space, and that really gives me a framework".

In a similar vein, Bex and Lisa used the flexibility of the structure to make explicit comparative links. For example, Bex made explicit the contrast between official letters related to her discharge and her account of what it was like for her to find out her therapist had died (image 6.2, 6.24 and 6.25).



Image 6.24 Bex's zine

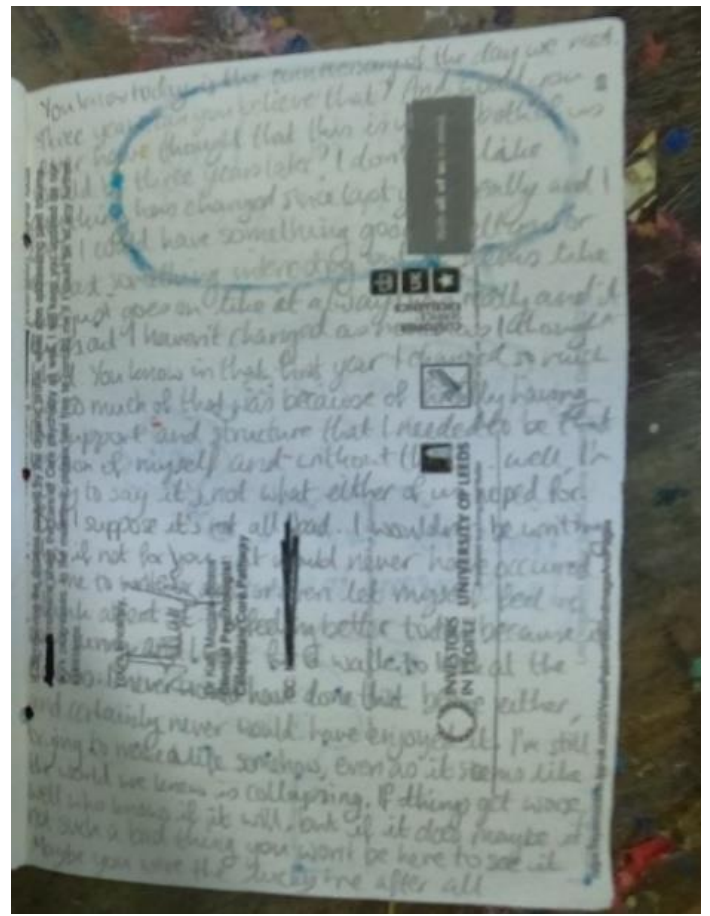


Image 6.25 page from Bex's zine

Lisa made explicit the contrast between her hopes and expectations of a trip to Vancouver and her experience of ending up in an emergency room psychiatric ward in Vancouver (image 6.26).

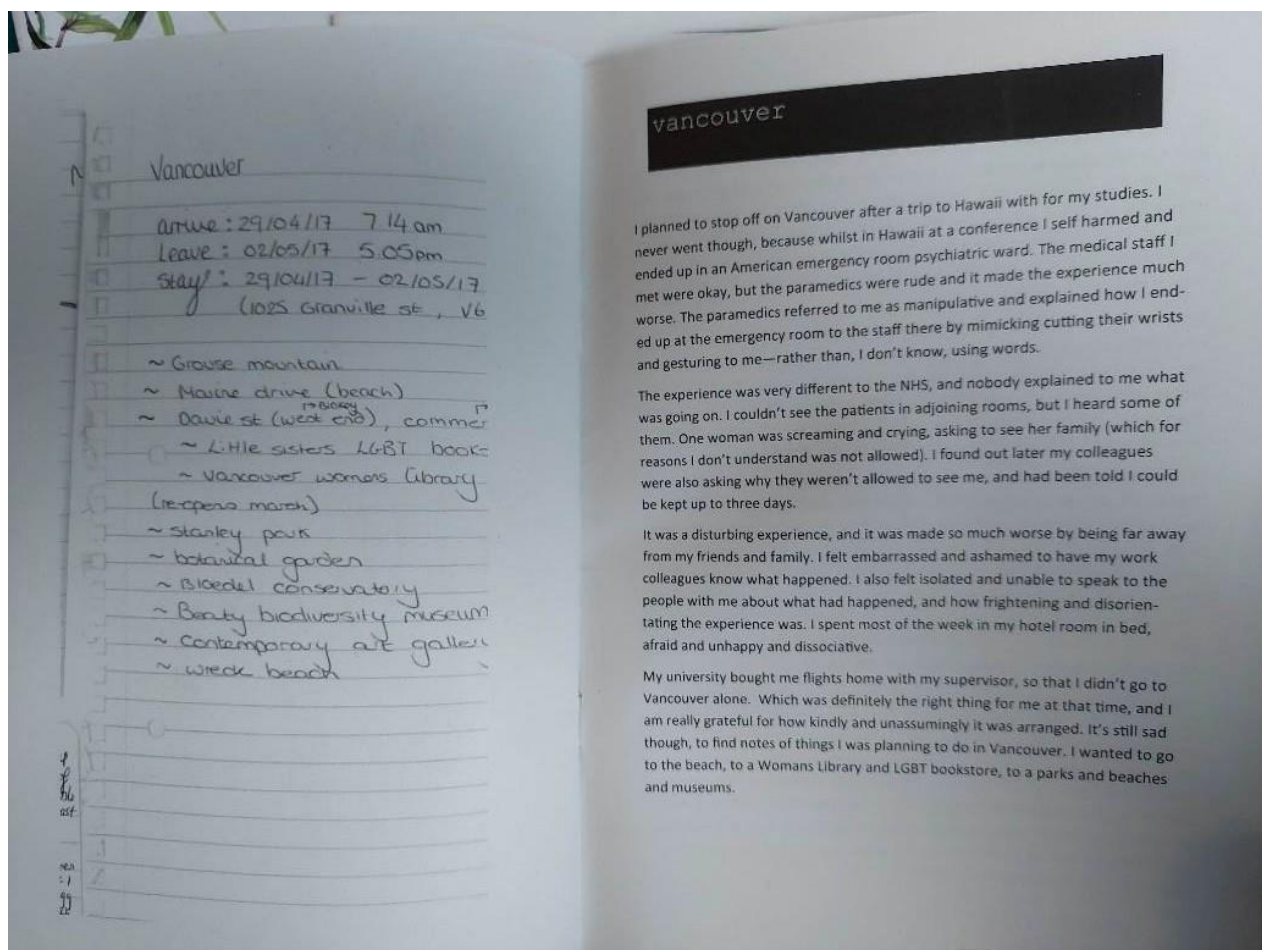


Image 6.26 Lisa's zine about having mental health crisis whilst doing a PhD

Similarly, in my *Pandemic Triggers* zine about the Covid pandemic, I made a thematic link explicit through grouping images and text about the elements of the pandemic I found most difficult (image 6.27 and 6.28). In my *Conversations with Mental Health Workers* zine, I made a thematic link explicit through grouping together images and text about conversations I'd had with mental health workers (images 6.30, 6.31 and 6.32).

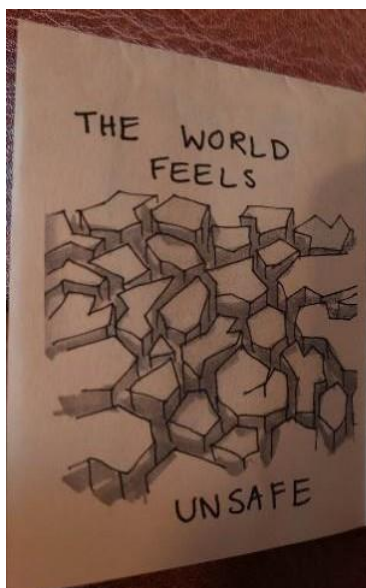


Image 6.27 Pandemic Triggers zine

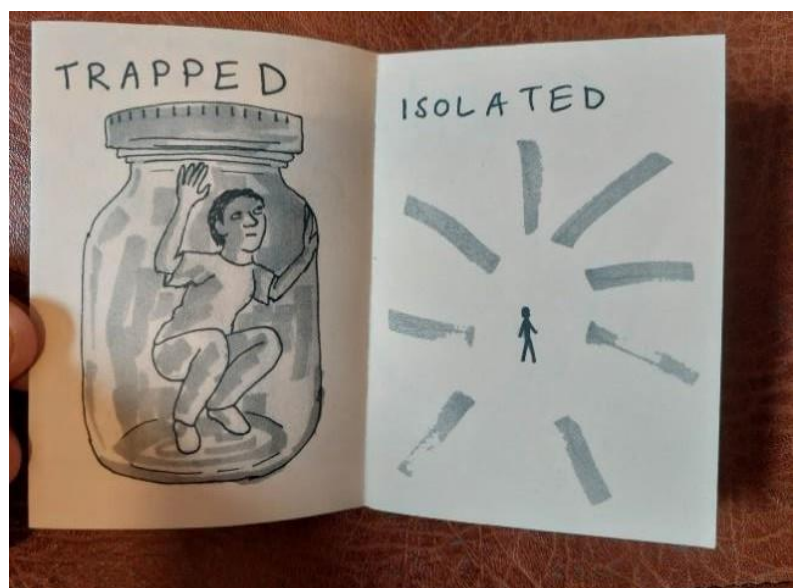


Image 6.28 Pandemic Triggers zine

Whilst it is possible to articulate contextual, comparative and thematic links using a linear structure, in my experience, being able to develop a structure around the links instead of trying to fit information into a linear structure enables these links to be more easily made and articulated. This may be because linear structures lend themselves to sequential links and thinking. In contrast, using a non-linear structure can enable us to show information in parallel, overlapping (as Bex and Lisa do) or grouped together (as in my zine). In turn, this can help clarify the ways in which experiences are similar or different to each other. Non-linear structures may also enable us to map numerous links that are not part of a sequence. For example, we can use them to illustrate how a personal experience is interlinked with the immediate, social and wider political contexts (as Annie does). This makes sense if we think about how we tend to articulate time sequentially on a linear timeline but create maps to illustrate the multiple ways that geographical areas are interlinked. If, as I outlined earlier, some survivors are more likely to think in patterns, then it may be particularly important that we have the opportunity to create different patterns/structures and, in this way, make explicit links. The process may suit our ways of thinking and enable us to make sense of and articulate our experiences in a way that works for us. I see the process of making interpretations through creating links like this:



Image 6.29 Interpretive connections

If we don't understand things through sequencing them, we may be able to understand them by arranging them in different ways. Bex, Dolly and LJ all spoke favourably about non-sequential structures representing how they think. Bex said she liked being able to make pages that were self-contained and not part of an overarching narrative as this suited how she thinks. Dolly spoke about being able to use a creative process in which the form could emerge from the process and related this to her being someone who doesn't think or speak in a sequential form. LJ said the flexibility of the zine structure enabled them to articulate their non-sequential thought process.

Making tentative links and exploring which things may be linked could be described as sense-making in process. However, if zinesters make links explicit and come to realise how different pieces of information and aspects of experience are linked, we have interpreted the information and developed an understanding of it. It is like the difference between creating a chronology and a story. In a chronology details of events are simply arranged in an order (in which they happen), and in zines information is arranged in an order. In a story we have created meaning from the order, as we have in zines where the quality of the link between information is made explicit. The quality of the links represents our understanding.

Making links as a process of interpretation

For me, the flexibility of the zine structure enables me to create and then make explicit various types of links, which in turn enables me to interpret the information and come to a conclusion about it. For example, I will often draw and write about different elements of a topic, and then physically move these elements around to see which page, image or chunk of text relates to which other piece and in what way. The flexibility of the zine-making form means I can create different types of links. Being able to see the connections then enables me to think about the quality of the connections and come to conclusions about these.

For example, when I made my *Conversations with Mental Health Workers* zine, the flexibility of the structure meant I could make non-sequential links between things that were said to me, and things that happened, and didn't happen, when I was in mental health services. The process of making non-sequential links highlighted to me the contrast between what services said they did and what different mental health professionals actually did. In turn, this helped me to understand that my difficulty trusting mental health professionals is because I have experienced them as inconsistent. I wouldn't have gained this understanding if I had tried to create a sequential narrative.

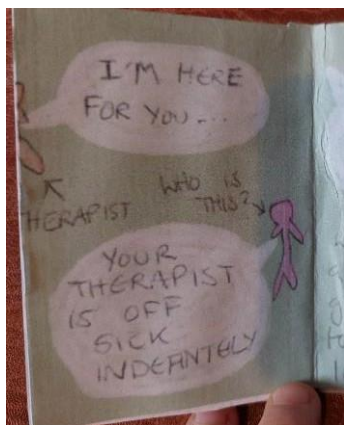


image 6.30 *Conversations with mental health workers* zine

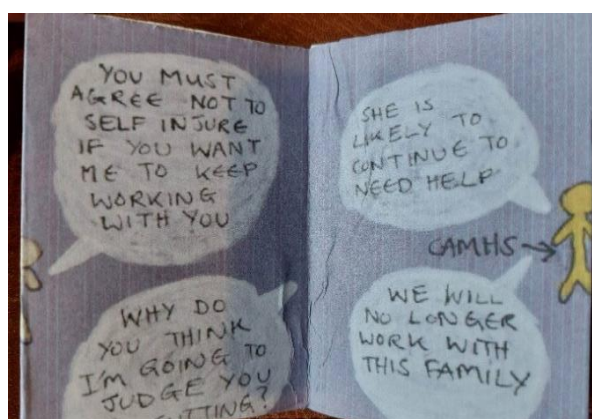


image 6.31 *Conversations with mental health workers* zine

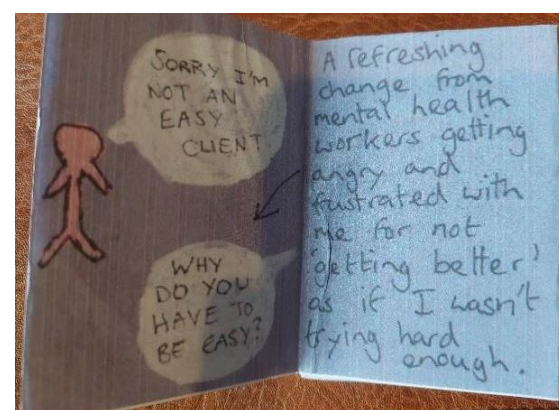


image 6.32 *Conversations with mental health workers* zine

Similarly, in my *Pandemic Triggers* zine (images 6.27 and 6.28), it was through the process of identifying, illustrating and bringing together qualities of the pandemic that I was able to understand that part of the reason I found the pandemic so difficult was that it reminded me of other difficult times and experiences. This was possible because I was able to group the elements instead of sequencing them.

As well as being able to make interpretations through trying out different links during zine-making, I found the process of putting things on paper, in the order I experienced them, helped me make sense of why I experienced them in this way. For example, many of links in *Not My Shame* represented the order in which I experienced those things but the process of putting these on paper became a process of understanding how and why I experienced them in this

way. It was a process of understanding how and why different events were linked for me, not just a process of articulating the order in which I experienced them. By articulating my non-linear internal timeline, instead of an external timeline, I came to understand how the qualities of one experience threw me into a trauma response, which is much more useful to me than knowing exactly which event followed on from another. If I had articulated the external timeline, I would not have gained any understanding because one event did not lead to another. The only way in which the events were linked was through sharing similar qualities and the way they made me feel. In contrast, like LJ and Annie, I've had the experience in services of being asked to create some kind of external timeline or temporally ordered account which I find difficult to do and which doesn't help me to make sense of my internal experience.

However, although the process of creating or articulating links in zines can be a process through which people might develop interpretations, these interpretations are not always obvious to readers. If a zinester hasn't explicitly spelt out what they think these links illustrate, their readers may come to a different understanding or may conclude what they are sharing is incomprehensible. This may be a particular risk when people make links between bits of information in a non-sequential or non-linear way. Whilst readers of a chronical may infer that one event led to another because we are familiar with, and expect to read, narratives with causal links, readers of non-sequential texts may not recognise the implication of the links made. For example, whilst I may see the non-sequential links that Annie, Bex and Lisa make as representing interpretations based on context and comparison, other readers may read these texts differently.

Involving readers in non-linear sensemaking and limiting exposure to criticism

When survivors share zines with loose, tentative or implicit links, they are sharing information in a way that the reader can then interpret. In other words, sensemaking can happen across and

between the process of the zinester creating the zine and the reader reading it. I see this process like this:

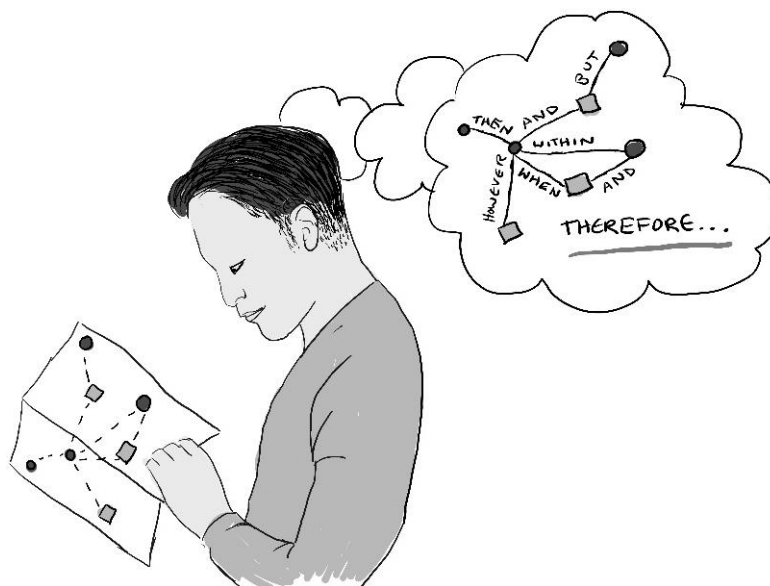


Image 6.33 Reader interpreting links

I have already written about how survivors might benefit from being able to create and share zines with loose tentative or implicit links if they have low epistemic confidence, are worried about how their interpretation might be received, or find an experience difficult to make sense of. However, survivors can also make and share zines in which explicit links haven't been made because they want the reader to interpret and make sense of the text and the links. There may be many reasons for this. For example, it might be because they have low epistemic confidence or because the experience their zine is about is difficult or impossible to make sense of.

One survivor (LJ), described this as being like inviting the reader to take part in the sensemaking process:

"In some ways it is ... being like, 'actually I can't make sense of this, so you try'"

LJ explained that using tarot as a form of non-linear storytelling in their *Mad Tarot* zine enabled them to articulate the past and keep it relevant without having to create a sense of coherence and continuity (image 6.34, 6.35 and 6.36). Whilst the creative process was about trying to find

meaning, and they included notes to explain some of their thinking (image 6.36), the cards also stand alone as representations of different elements of LJ's experience that the reader can reflect on. The zine represents a process of reflection, not a definite and explicit conclusion or argument. The elements are gathered in the zine and the reader is actively invited to try and create their own understanding.

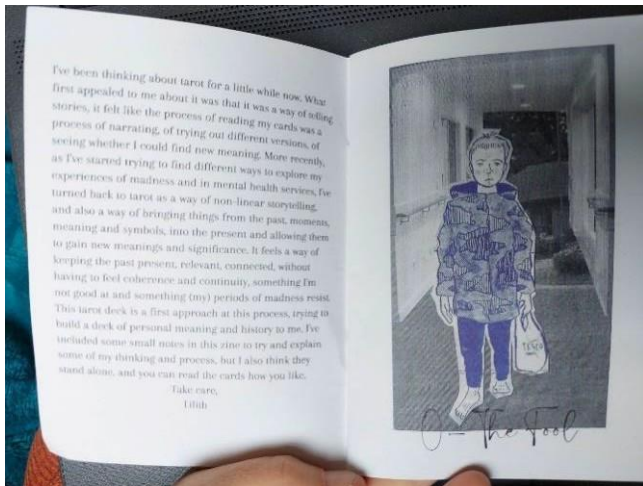


Image 6.34 LJ's Mad Tarot zine



Image 6.35 LJ's Mad Tarot zine

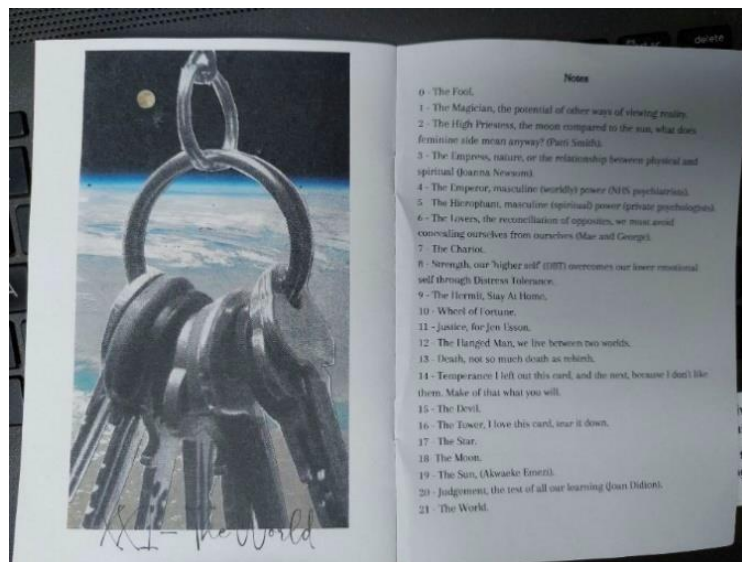


Image 6.36 LJ's Mad Tarot zine

LJ described not having to make explicit links and interpretations of experiences before sharing them as enabling them to share reflections on experiences of madness that they otherwise wouldn't have been able to share:

"Some stuff just doesn't get resolved. Like, what does what did this mean when that happened or when I watched this happen? I still don't know so I couldn't say anything definite to another person ... I can just be like 'this is how I remember it happening and I don't know what to do with that memory...someone can read into that what they want, but you're not doing the work for them" (LJ)

LJ also described this as handing over some of the work to the reader and thinks we shouldn't have to make sense of things before we share them:

"Maybe this demand to make sense of this is unfair and I shouldn't have to do that work to make sense of it for you so I can tell you about it."

For LJ being able to create and share a zine in which the qualities of the non-linear links were not explicit, enabled them to articulate and share experiences of madness without having to first make sense of them. It gave them the opportunity to invite readers to make sense of it.

When I have created zines with loose, tentative and implicit links, it was usually because I didn't feel confident in my interpretation, because I didn't trust or value the interpretations I had made, because I didn't feel I had the right to make an interpretation, or because I wanted to see if others would interpret information in the same way I had. In other words, it was in part because I had what Fricker (2007) might call low epistemic confidence related to internalising the way that I was not conceived as being a capable epistemic agent in the MH system. As a result, I was fearful that my interpretations would be dismissed, severely criticised and/or used

to pathologise me or used to argue that I am not epistemically (or mentally) competent. In other words, it was because I was fearful of experiencing testimonial injustice and epistemic objectification and because I saw my interpretations as what Dotson (2011) might call risky testimony. In a context where survivors are conceptualised as lacking epistemic capacity, the very act of making an interpretation can feel risky because, by using and valuing our epistemic capacities, we are challenging the ways that we are conceptualised and perceived.

Therefore, using zines to share experiences without explicit interpretive links and so inviting readers into the sensemaking process may enable experiences to be shared that might not be possible to share otherwise and the work of interpreting the experience is shared with the reader. This approach can also enable survivors who are fearful of sharing interpretations, and/or who lack epistemic confidence, to share experiences. However, it risks survivors' experiences being interpreted in ways that we don't like or in ways that might be harmful to us. The impact of sharing the sensemaking process with readers will depend very much on who our readers are. I explore the context in which zines are shared and who readers are in chapters 8 and 9.

Summary

The flexibility of zine structure was important to survivors who didn't want to exclude information that they couldn't fit into a linear structure. Because survivors were able to create structure to fit the content or the links they wanted to make, they were able to decide what they felt was relevant or how they thought elements might be linked instead of excluding content that didn't fit a set structure, or which they couldn't link sequentially. It is significant that survivors chose to use non-linear structures when creating their zines because as I outlined earlier, survivors are often expected to use linear structures and can be pathologized for not using them. In addition, non-linear testimony can be perceived as nonsense, and more generally, there is an expectation that we use linear narrative.

The flexibility of zine structure meant that survivors could reflect on and articulate experiences that they might not have been able to otherwise. Some survivors used the space created by the flexibility of zine structure to articulate and share the richly detailed descriptions and complex information they felt was relevant to the topic and include ideas that wouldn't fit within a preset structure, or which were not part of a single cohesive argument. Some survivors used the flexibility of structure to reflect on and articulate things they experienced as non-linear, including time, sense of self or memories and some survivors used the flexibility to contextualise and/or make comparative or thematic links. In other words, the flexibility of structure created space in which non-linear experiencing and thought processes could be articulated. This is significant because sometimes survivors can't separate their mental health experiences from their experiences of services, so non-linear structure enabled them to reflect on their experience of services. It is important that the flexibility of structure enabled survivors to include details and contextualise experiences because as I outlined earlier, the interpretive resources relied on in the MH system often simplify and decontextualise survivors' experiences e.g. diagnostic frames within which survivor experiences are understood simply as mental illnesses. Finally, it is also significant that the flexibility of structure enabled survivors to make contextual links because survivors must be able to articulate and understand the links between our individual experiences and the social, political and culture contexts if we are to be able to identify the social, political and cultural changes that we might benefit from. Notably, there is limited literature which relates the physical structure of zines to what it might be possible to articulate or how ideas might be organised/structured within zines.

The process of making links and developing structures can be a process of interpreting information and coming to conclusions about it. The process of articulating pre-existing links can also be a process of clarifying and coming to an understanding about the qualities of the links. Therefore, you might argue that zine structures can be interpretive resources.

Whilst it can be beneficial for survivors to make non-sequential links in their zine-making, the understanding that emerges from the process may not be visible to the reader. In other words, whilst being able to make a variety of links can help survivors make sense of our experiences, if we want to communicate our understanding to readers, we may have to be explicit about the nature of the links and our reasons for making these links.

Some survivors used the flexibility of zine structures to link contents loosely, tentatively and/or implicitly. In this way, their zines can be seen to represent the information gathering and exploratory stage of knowledge-making where the interpretation and sensemaking is tentative, or in-process. Some survivors saw not sharing explicit links and interpretations as a way to invite the reader to make their own interpretations, and even to invite them into the knowledge making process.

Survivors can have different reasons for sharing zines in which they haven't made (explicit) interpretations. There are links between doing this and the particular challenges survivors face when it comes to articulating and sharing our experiences. Sometimes survivors didn't make explicit links and interpretations because they hadn't been able to make sense of an experience, and sometimes it was because they didn't feel confident, or it felt risky to explicitly share their interpretation. Both of these concerns are related to experiences of madness or services, in other words they are related to zinesters being survivors. Experiences of madness were described as extremely difficult to make sense of and one survivor found it useful to be able to reflect on and articulate this without having to interpret it or make sense of it. Being able to create and share a zine in which they didn't make explicit links enabled them to share accounts of their experiences of madness and services that they wouldn't have been able to otherwise. At times, whilst I haven't made links and interpretations explicit because it felt risky to share my interpretations, or because my confidence in my epistemic ability was low, this felt

linked to my experiences in services. In other words, sharing implicit interpretations is a way to protect myself from the potential risk of sharing explicit interpretations.

When links are implied or tentative without an explicit linear narrative, conclusion or argument, it is open for the reader to interpret. This means sensemaking can happen across/between the process of the zinester creating the zine and the reader reading it. This might mean that we benefit from the interpretation of another survivor who reads our zine. However, it can also make survivors vulnerable to having readers (mis)interpret or pathologise what we share.

The risk of being harmed by misinterpretation will depend on the context in zines are shared, how they are shared, who they are read by, and the position of the reader-interpreter in relation to the zinester. Whilst experiences in the MH system might lead some survivors to expect our interpretations to be unwelcome or difficult for our audience to recognise, as Dotson (2011) points out, how testimony is responded to will vary depending on who the audience is.

Therefore, the following chapter will focus on how different qualities of zines were experienced by readers and in the last two chapters I write about the context in which zines are created and shared, and who the audiences for these zines are.

Engaging with zines

In this chapter, I focus on how different zine qualities might help survivors share experiences and understandings with readers. I explore how the possibility of using visual, sculptural and unusual elements in zines can affect what knowledge can be shared and how this might be received by readers.

Again, I draw on interviews with all my participants and all the zines they shared with me or made as part of the research. However, I primarily focus on the zines made by the survivors that I introduced to zine-making and readers responses to these because I had direct access to information about how multiple people responded to these zines, whereas with the other zines I only had access to my own responses/reading and what the zinesters said about that.

Specifically, I draw on my observations from the session in which participants shared their zines with each other; comments these participants made about reading each other's zines; and my experience of reading their zines.

Firstly, I write about how, why and to what effect survivors use visual communication to share experiences and understandings. Secondly, I describe how, why and to what effect survivors use sculptural qualities and unusual structures when sharing testimony. Thirdly, I outline how, why and to what effect survivors used zines as a creative object when sharing zines.

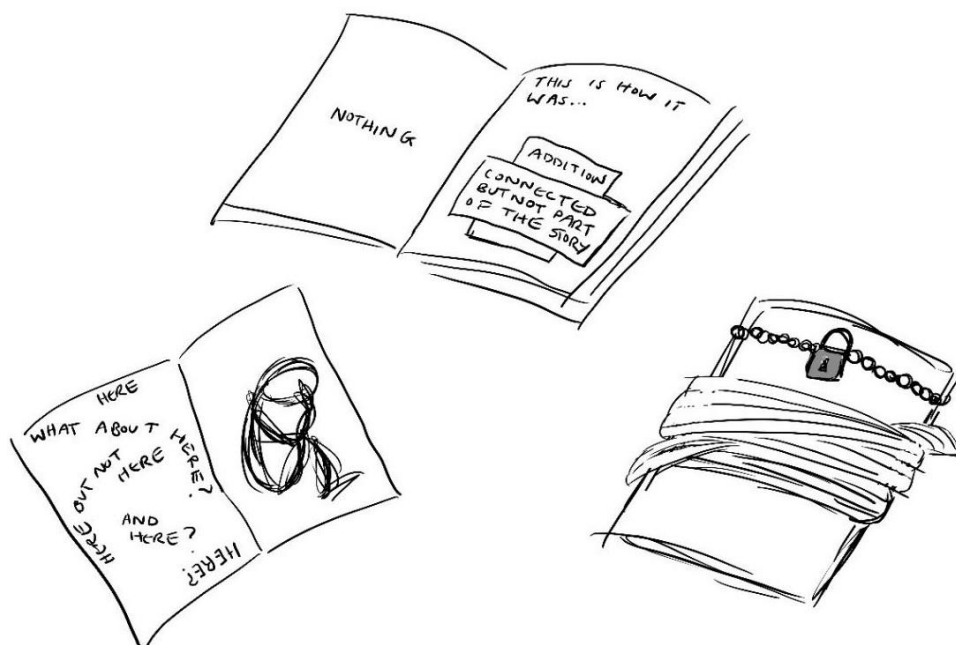


Image 7.1 Visual, sculptural and unusual structure

Visual communication

In this section I will outline how why and to what effect survivors used visual communication in their zines. I will also outline how combining visual communication with text mitigated some of the limitations of visual communication and vice versa. When I use the term visual communication I mean images, and things like line, shape, colour, visual texture and choice of font. In this definition the font in which a word is written conveys a visual meaning whereas the word itself conveys a textual meaning. For example, the word danger written in comic sans font (danger) can visually communicate a playful, childish or comic quality even though the word itself conveys meaning related to risk and threat.

All the zines research participants shared with me or made as part of this study included a mixture of text and images and/or visual elements. The balance between these varied between survivors and between zines. In the zines that experienced zinesters Annie, Kirsty and Mary shared with me, most pages contained a mixture of text and images/visual communication but the weighting between these varied from page to page. The survivors I introduced to zine-making also chose to combine text and visual communication in their zines. In the zine Nicola made

there was a combination of text, images and other visual communication on each page and the weighting between these was fairly consistent. In Diane, Nazrah and Kaz's zines the balance was much more varied: some pages were entirely text, some pages were entirely visual communication, and some pages were a combination of both. All the pages of Bex's zine had a visual element and the balance also varied, most had a combination of text and visual communication, but a couple of pages were entirely visual.

Some survivors said they used a combination of text and visual communication because they believed this would increase the chances of readers understanding what they were trying to communicate. For example, Kirsty said she combines images and text because she believes this will make her zines easier to read; Mary said: *"As a teacher I know kids learn differently and so I try to put it in multiple ways so that people can connect to it"*; and Nicola said that she thought using both would help readers *"understand better"*. I occasionally make zines that are entirely visual or entirely textual, but I tend to use a combination of both. I do this because like Kirsty, Nicola and Mary I believe/hope that this might help readers access or understand what I am trying to communicate. Often this is a matter of annotating images because I think it helps readers understand what I'm trying to communicate. For example, in one of my zines about epistemic injustice I annotated the images I had drawn about the prejudicial evaluation of testimony. Whilst my personal relationship to the visual element of the image means that the image itself communicates prejudicial evaluation of testimony, for other people, this meaning would likely not have been communicated without the addition of text on the image.

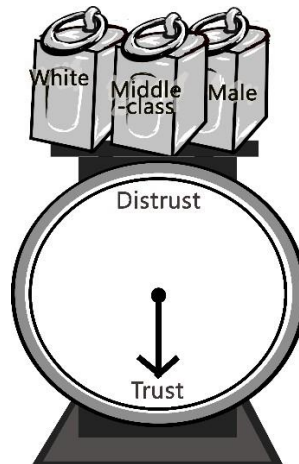


Image 7.2 Prejudicial evaluation of testimony

Although as I outlined in chapter 5 some participants told me that using image was important to their process of articulation, when reading other survivors' zines none of the participants described their understanding as coming exclusively from images or visual communication. Instead, we tended to find that visual communication added to or enriched our understanding of the survivors' experiences and emotions.

For example, when reading Nicola's zine (see image 7.3) two participants commented on an annotated image which showed physical symptoms drawn on a body and said this added to their understanding of what the physical condition of Scleroderma might feel like. These participants also commented that this image helped them appreciate the stark contrast between what a person might be experiencing and what others could see. For example, Diane said of the annotated picture:

"You can see the difference when you look at that. It helps you understand. You can see how it feels."

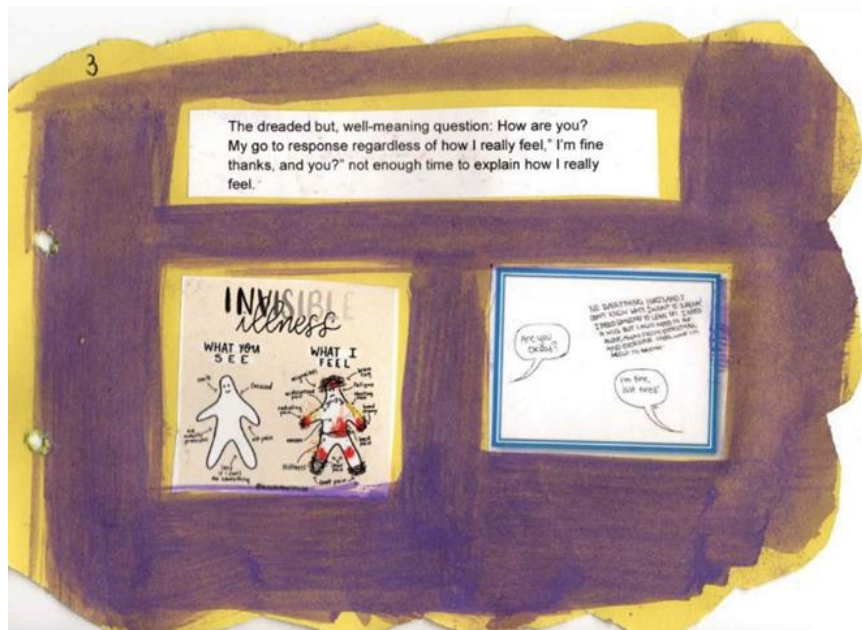


Image 7.3 Page from Nicola's zine

When I read Nicolas's zine I had a similar reaction to the annotated image. My understanding of how Nicola might be affected by this condition came from the combination of all the text, including the line from her poem, and the visual elements she used on the page. The visual communication aided my understanding, but I wouldn't have gained the same understanding from either visual communication or the text alone. The line from Nicolas's poem gave me the context of her specific experience; the image helped me see the contrast and gave me a sense of the pain; and the annotations helped me understand the context/details of her experience of pain. When reading Nicola's zine, I was also struck by her signpost drawing, combined with the line from her poem about the impact of becoming ill. This image really helped me understand the contrast between before her illness and after it and how becoming ill was a crossroads and a lifechanging moment for her (see image 7.4).

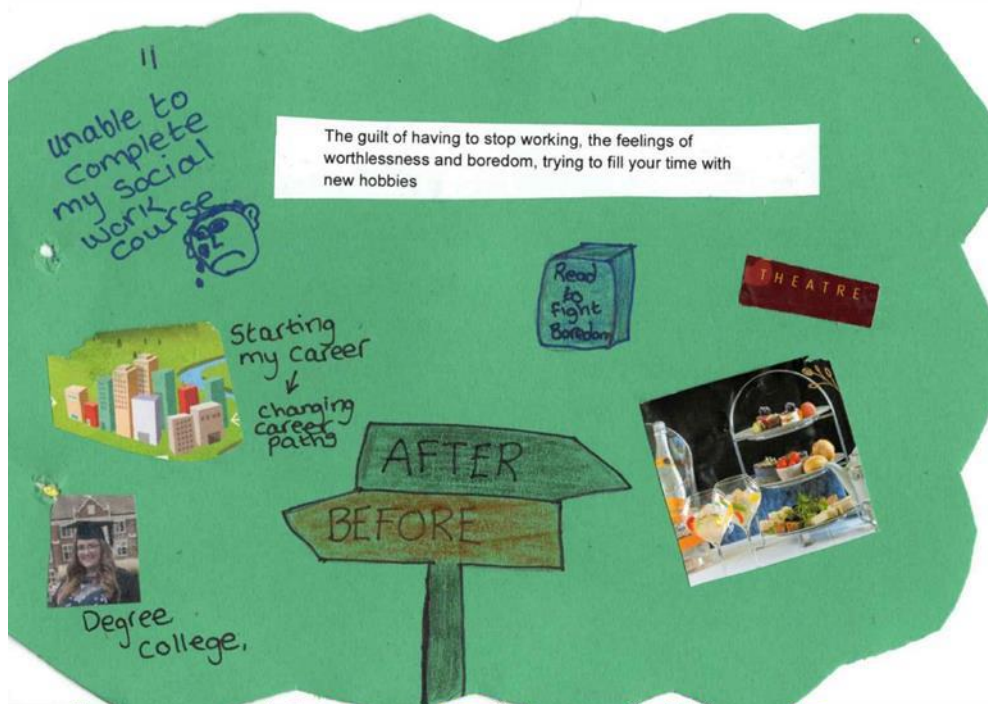


Image 7.4 Page from Nicola's zine

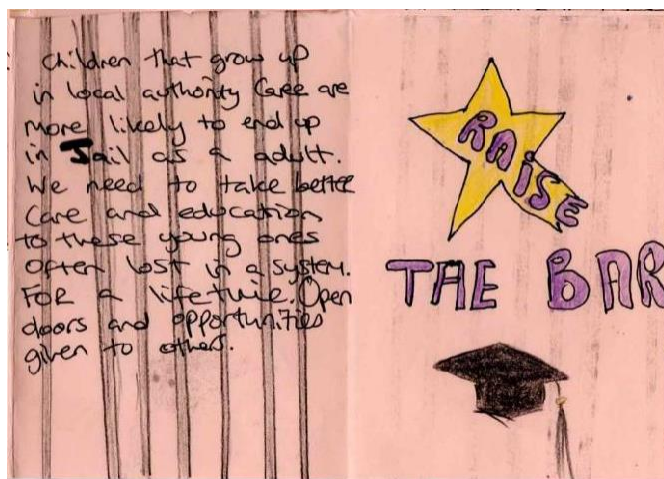


Image 7.5 Page from Diane's zine

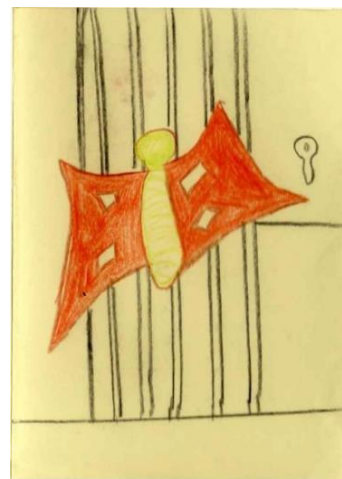


Image 7.6 Page from Diane's zine

Similarly, when I read Diane's zine (see images 7.5 and 7.6) her use of imagery combined with words really helped me perceive and understand the quality of contrasts. The symbols combined with text on pages 4 and 5 of Diane's zine (image 7.5) showed some opportunities and aspirations that children in care don't have. It enabled me to see and understand the stark difference between having and not having these opportunities. The image on the back page of Diane's zine (image 7.6), of a butterfly in front of bars, illustrated to me the contrast between

being subject to barriers and being free of them. In combination with the words on previous pages this image gave me a sense of the transformative impact of removing barriers for children in care. I don't believe these contrasts would have been as clear to me if Diane and Nicola hadn't used the visual communication they used on these pages and so my understanding would have been limited. I also don't believe I would have understood the context for the images without the accompanying text, despite being someone who prefers visual communication to text. Although other participants didn't explicitly comment on this aspect of Diane's zine, other than to say that they liked the images and the way she had used them, Bex indicated that one of the images helped her better understand what Diane had written and specifically referred to the image of the butterfly in front of the bars: *"I like the contrast. It helps show what you mean"*.



Image 7.7 Visual contrast

When I read Nazrah's zine, I felt that I was able to understand what she wanted to communicate when the pages contained both images and text. For example, on one page there is a drawing of people socially distancing on a bus and underneath, the words, "don't split people up". I understood this as criticism of the policy to socially distance on public transport and this was confirmed when Nazrah spoke about her zine. On another page there was a drawing of a mask and accompanying text saying, "It isn't over yet, wear your mask" and Nazrah confirmed my understanding that this was about her wanting people to wear masks. However, where Nazrah's

pages contained only images, I found myself struggling to understand what they were about until she explained them to me. For example, one page was a drawing of a woman surrounded by Covid viruses which Nazrah explained was about the Government making people afraid by showing viruses in that way; another page was a drawing of a woman sitting looking at a computer; and another was a picture of two women having a cup of tea and talking. Nazrah explained these pages were about how important it was to be around other people in real life. I found these pages difficult to understand until they were explained to me, even in the context of the zine as a whole. The text was important to orientate me to the images, to give them context in a similar way to how the words on the page before Diane's butterfly image helped me to understand that the image was about removing barriers for children in care. Nazrah chose not to share her zine with other participants so I was the only person who read her zine. The image below represents my experience of reading Nazrah's zine (image 7.8).



Image 7.8 Emotion with uncertain context

In some cases, the use of visual communication in survivors' zines helped communicate emotion to readers. This is in line with literature about visual media communicating emotion or

eliciting emotional responses (Cameron, 2012; Batey, 2024). For example, when other participants read Bex' zine, they all responded to and commented on the emotions that the visual images evoked in them such as feelings of distress, pain and loss Kaz said the visual communication gave her a sense of things being “dark” and “intense” (image 7.7), whilst Diane described the visual communication as giving her a sense of Bex's “loss” (image 7.9) and “anger”(image 7.13).



Image 7.9 Page from Bex's zine

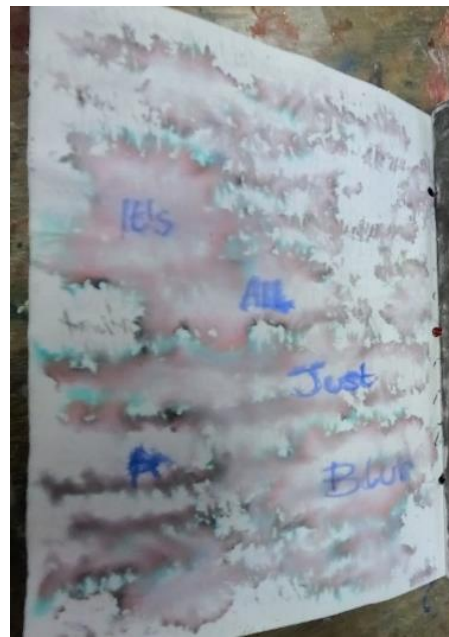


Image 7.10 Page from Bex's zine



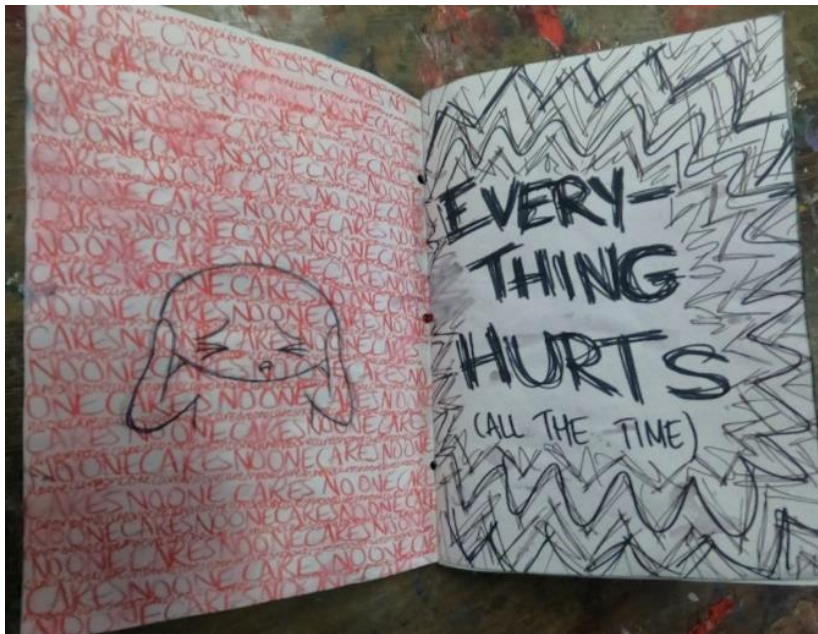


Image 7.12 Page from Bex's zine



Image 7.13 Page from Bex's zine

Similarly, when I read Bex's zine I found her images impactful and evocative. I gained an understanding of her feelings of pain, loss, sadness, rage and disconnection from the visual communication as well as the words this was combined with. I often got a felt sense from the images and then this was clarified or contextualised by the accompanying text. For example, on page thirty-one (image 7.11) the red and gold marks on a black background gave me a sense of darkness, densness and heaviness whilst the word "suffocating" at the top in barely perceptible writing and the word "shame" at the bottom that is fairly difficult to read indicated to me what the senses of heaviness, darkness and denseness related to. The image of a person with their head in their hands (image 7.2) gave me a sense of distress whilst the words "no one cares" told me what the distress was about and the way the text was repeated covering the whole page indicated the extent of the distress. The sharp corners gave me a feeling of pain whilst the words gave me more information about the pain. The translucent image of a sad figure with blurred edges (image 7.9) gave me a sense of seeping sadness which was backed up by the text. The red handprint (image 7.13) gave me a sense of danger, which the words helped me understand as rage. In combination the image and the text gave me an understanding of the strength of the rage. The blurry imagery (image 7.10) gave me a sense of disconnection and confusion which was clarified by the text explaining that "it's all just a blur".

If Bex had articulated her zine only in text or images, it would not have had the same impact on me. I might have understood that she was hurt, grieving and angry but I wouldn't have had the visceral understanding of what it meant to feel those emotions that I gained from engaging with her zine. I also think that without the text my understanding would have been purely visceral, I would have had some sense of the emotions but not appreciated the qualities, specifics or the context.

Unusual structures and sculptural elements

As I describe in chapter 6, non-linear structures were common amongst participants' zines. Sometimes their zines had complex structures and sometimes this was linked to them having sculptural elements in the sense that the zine's structure was three dimensional. In addition, some survivors' made use of sculptural elements that were not related to structure. For example, sewn elements (Rin and Bex), unusual sized and/or shaped pages that were not always connected to the main body of the zine (LJ, Nicola, Kaz and Bex), the use of materials other than paper (Bex, Kaz and Diane). Here I describe readers responses to unusual structures and sculptural elements, what survivors hoped their use of these might achieve and reflect on how effective using these elements was at achieving survivors aims. I focus on Bex and Kaz's zines as they made most use of sculptural elements and I describe how the other participants and I responded to these zines in the context of workshops and the zine sharing session.

Bex's zine

Bex's zine has the most extensive use of sculptural elements. In addition to having a very complex and unusual structure, her zine had multiple hidden and non-hidden inserts including a mini zine and torn fragments; a page that was torn in half; a page that opened down the centre; a page which was almost entirely covered with earth; a page which had sewn elements; and a page to which masking tape had been added. Finally, the zine itself was chained closed

and padlocked, the chain had a stopped clock on it and the whole zine was wrapped in a bandage. It is almost impossible to show this via a flattened image or picture.

Bex felt that using a complex and unusual structure and sculptural elements enabled her to evoke in the reader some of what she was experiencing. Specifically, she spoke about trying to create in the reader a sense of disorientation and a feeling of searching unsuccessfully for something as these sensations were part of her response to finding out that her therapist had died. She related this to the way some pages were physically hidden, the expected reading order wasn't clear, and some text was within unusual page structures.

When I was reading Bex's zine, and finding hidden compartments and working out where to look next, she said:

"You have to really look. I did it on purpose. You're not supposed to know where things are, or what to read next. It's meant to make you feel lost. I want you to feel some of what I felt...I'm deliberately making people feel, unsettled and disorientated. I'm making them feel like they are searching for something that isn't there and they don't know what to do, like I felt when I found out my therapist had died."

In addition to communicating a sense of her experience, Bex saw her use of sculptural qualities and unusual structures as a way to prevent readers from merely observing the contents. As I read her zine at the end of the final zine sharing session Bex drew attention to hidden fragments that a reader might try and assemble Bex commented:

"You have to interact; you can't just look at it like a book. You have to explore it."

Bex further spoke about how her use of unusual structures and sculptural elements would mean readers have to make an effort to access the contents. Bex said:

“People who don’t really look won’t find the hidden compartments; they won’t know what’s in them.”

Bex said she intentionally put readers in a situation where they had to work to find the information in her zine. For example, one of the pages of Bex’s zine (image 7.14) includes a statement embedded in a collage and readers have to work out which words are part of the statement and which words are part of the background. As I read this page of her zine Bex noted:

“You have to make an effort. There is a sentence, but it’s hidden. You have to make an effort to find it.”

In the repetition of the word effort, it seems Bex appeared to be using unusual structures and sculptural elements to test her readers commitment, or willingness to exert effort, to access the content of her zine and understanding her experience (although these are not the words she used).

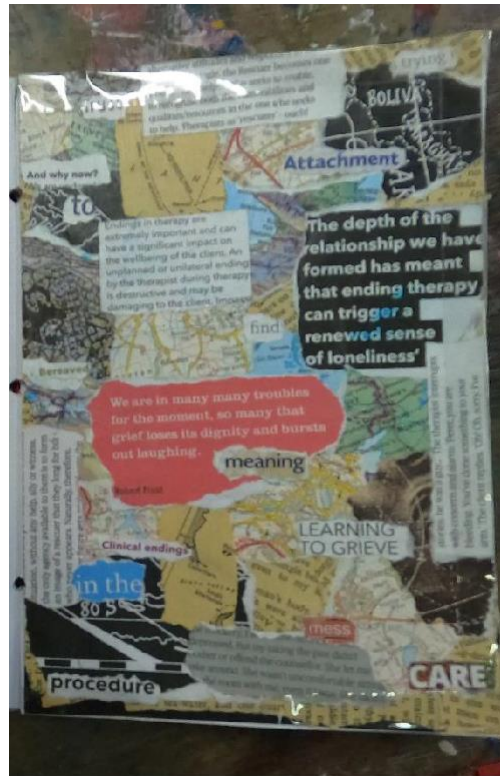


Image 7.14 Page from Bex's zine

When I read Bex's zine the structure of the zine as a whole, and the structure on individual pages resulted in me feeling disorientated and a bit lost. Where there were pages hidden between pages or inserts or fragments in pockets, I wasn't always sure in what order I should read different sections, which felt disorientating. In terms of individual pages, one page includes words in bubbles, the order of which is not immediately obvious (image 7.15). Not knowing which order I could or should read the words, or even whether or in what way this was important to its meaning challenged me and left me feeling uncertain as a reader. The criss cross of words on another page had a similar effect (image 7.16). When reading Bex's zine at the end of the final zine-making workshop Nicola also mentioned being disorientated by this and the overall structure of the zine and felt unsure how to read it. For example, when at the end of the final zine-making workshop she said:

"It's difficult to know what order to read it in, it's like with the whole thing, it's hard to tell where to start and what to read next".

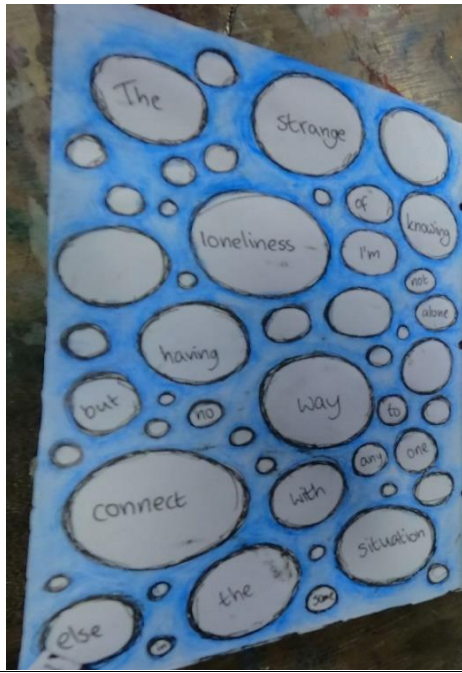


Image 7.15 Page from Be's zine



Image 7.16

Whilst the confusing structure made Nicola and I feel the sense of disorientation that Bex said she wanted us to feel, Nicola didn't speak about the disorientation in relation to the content of the zine and I'm not certain I would have consciously related my feeling of disorientation to my understanding of Bex's experience of losing her therapist if Bex hadn't spoken to me about this. However, it's possible that on a subconscious level the feeling of disorientation I experienced was connected to the content I read and so may have added to my understanding. Essentially, then, whilst the unusual structures conveyed some emotions, they were not always successful in conveying an understanding of what might be important in the content, or the context for the feelings that were evoked. Instead of the unusual structures enabling understanding through making connections, as described in my previous chapter; here the connections were unclear, the unusual structures were deliberately confusing and could be described as a metaphor for Bex's sense of disorientation.

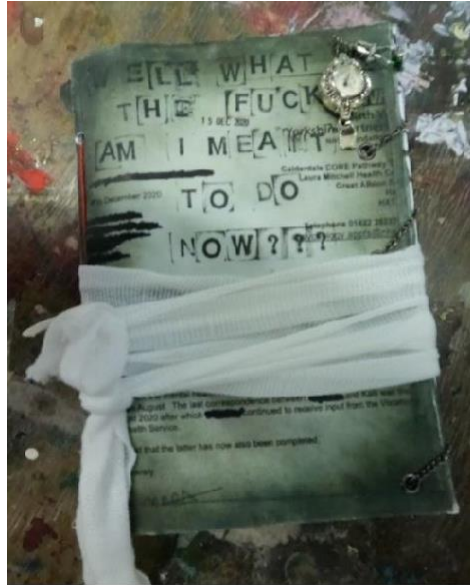


Image 7.17 Front page of Bex's zine bandaged and chained

To open and read Bex's zine a reader must first unbandage it, unlock a padlock and then unchain it (image 7.17 and 7.18). Like her use of unusual structures with hidden elements Bex's use of a chain, padlock and bandage might also be seen as a way of testing the readers commitment. The reader has to physically engage with Bex's zine and turn it over in their hands before they can open it. Participants had visceral and emotional responses to this when they read her zine during the zine sharing session or at the end of the final workshop. When other participants read Bex's zine during the zine sharing session they appeared noticeably uncomfortable about removing the bandages, unlocking the padlock and undoing the chain. All the participants who read Bex's zine were noticeably disorientated by finding that this combined with the upside-down writing on the back page which meant it wasn't immediately clear which way up the zine was or where they should start reading it (image 7.19). Two of them indicated that unlocking and unchaining her zine made them feel uncomfortable, like they weren't sure they should be reading it, but it made them feel it was precious and important. When reading Bex's zine in the zine sharing session Diane and Kaz didn't unwrap and unchain Bex's zine until Bex told them they could do so. As Diane unwrapped and unchained it, she said, *"I feel like I shouldn't"* and, in reference to the padlock, she said, *"it's like for valuables or something"* and

Kaz agreed. They both also indicated that the bandage gave them the sense that the zine should be treated with care. When Kaz re-bandaged Bex's zine she commented *"it's like when something's hurt and you're looking after it"* and Diane agreed. When Bex shared the zine with members of an art group, she said they responded in a similar way.

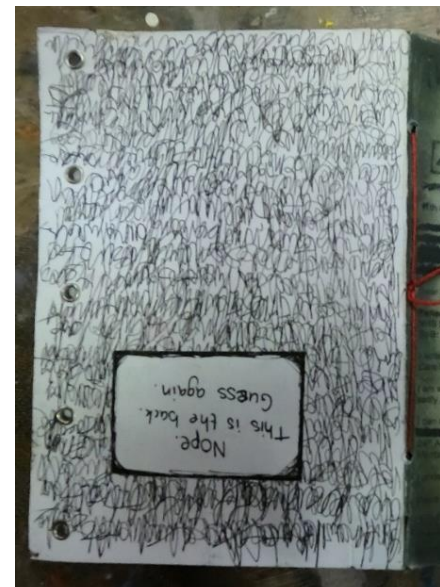
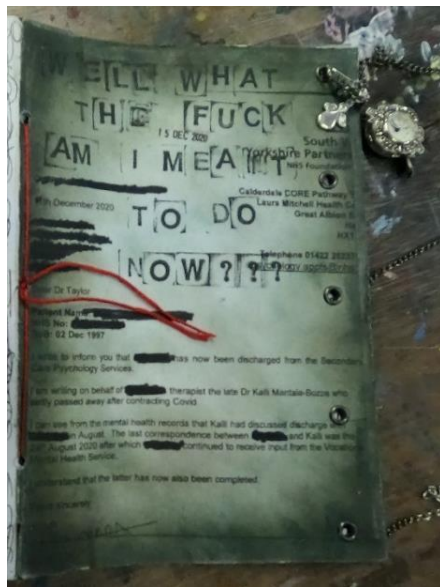


Image 7.18 Front page of Bex's zine unbandaged and unchained Image 7.19 Back page of Bex's zine

These elements of Bex's zine also elicited fairly similar emotional responses in me. When I read Bex's zine at the end of the final zine-making workshop I felt I was very much being asked to interact and take part in a process that was at times disorientating because it was not immediately obvious which order to read things in or where information might be found. When I unwrapped and unchained her zine, I felt a sense of care and tenderness, like I was being asked to care for something important. The padlock and chains gave me the feeling that although Bex wanted to share her zine, this was not an easy thing for her to do, and she wanted the reader to value it and care about what it contained. It also suggested to me that she might feel uncertain, cautious or in two minds about sharing the zine, although she had already spoken to me about its contents.

In addition to the padlock, chain and bandages, there were other sculptural (and sensual) elements of her zine which elicited visceral and emotional responses and understanding in me.

For example, one of the pages the words “Not crying like I used to and feeling pointlessly guilty” were scratched into soil (image 7.19). This gave me a sense of weightiness, barrenness and absence. It reminded me that this was a real-life experience, not an abstract idea. On another page, the fragments of an image in a pocket communicated to me the sense/feeling of a memory being destroyed and fragmented (images 7.20 and 7.21) and on another page the embroidery not only communicated to me a feeling of being constrained and unable to speak but gave me a visceral sense of that feeling (image 7.22).

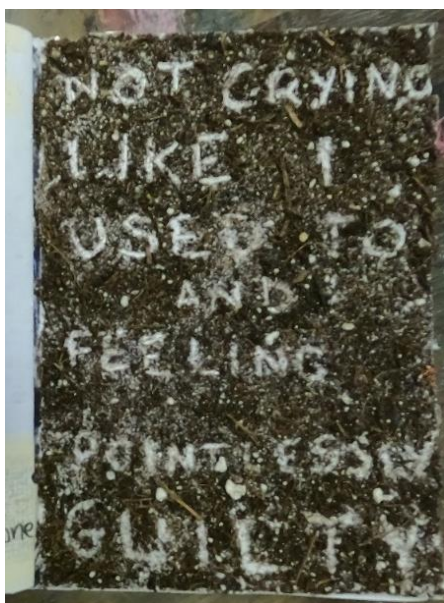


Image 7.20 Page from Bex's zine



Image 7.21 Page from Bex's zine

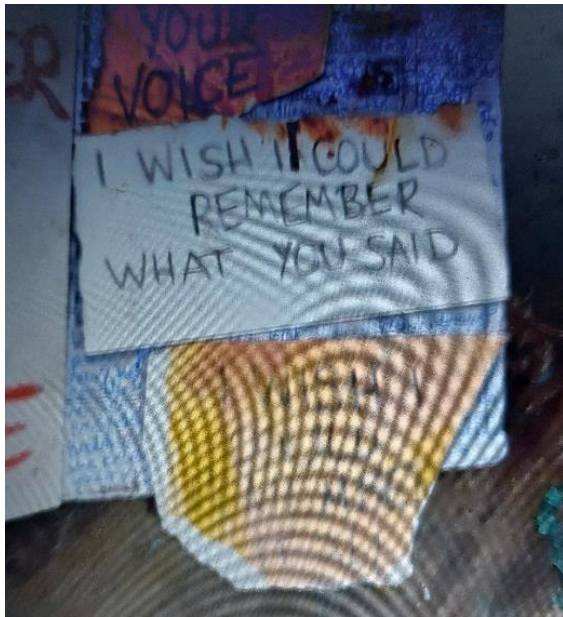


Image 7.22 Fragments in Bex's zine



Image 7.23 Page from Bex's zine

The way that Bex uses the unusual structure and sculptural elements of her zine to test the motivation and commitment of her readers could be seen as complimenting literature about how the sculptural elements of zines can make readers feel they have been taken into the zinester's confidence and invited to be an ally to their experience (Piepmeier, 2008).

Whilst Bex's readers are taken into her confidence through witnessing very personal, sensitive and emotional experiences, they must demonstrate commitment in order to access it. Bex may have tested her readers in this way because she did not feel confident in other people's commitment to want to understand her experience. Where an experience is particularly sensitive (as Bex's experience is), and if we have experienced people not making the effort to understand our experience or perspective (as Bex described having experienced in MH services), then it makes sense that we might want to test our readers.

The way in which other participants and I engaged with Bex's zine differed (see image 7.24). Whilst reading Bex's zine I felt I was being tested to see if I was interested and committed enough to make the effort and in spending the time looking. My response was to engage in a very active way and spend a lot of time exploring the zine. I found the unusual structure and

trying to discover the hidden elements in Bex's zine challenging, but I was interested in finding a way to read the zine and find the hidden elements, and I wasn't put off by the challenge. I found and received most, but not all, of the content that Bex had articulated and shared. At times the act of having to open different sections felt intrusive. However, I felt able to explore these the hidden elements because Bex explicitly made it clear that this is what she wanted me to. We had had conversations about what her zine was about before I read it and Bex encouraged me to access all the bits of the zine as she watched me read it. I would not have felt able to engage in such an active way and search within the zine for elements that were less obvious and hidden, otherwise. Feeling able to look for the hidden elements was also helped by the fact I had made, shared and wanted people to read zines which had similar formats.

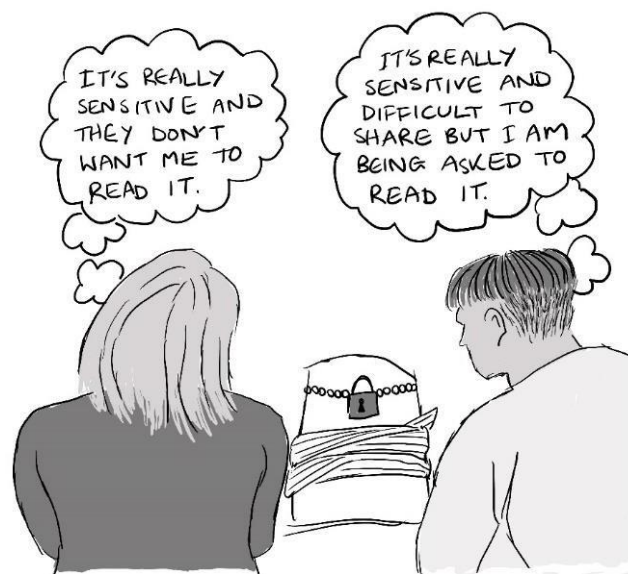


Image 7.24 Differing responses to sculptural elements

Other readers who read Bex's zine in the zine sharing session spent much less time with Bex's zine than I did, they did not look for what might be hidden and didn't read the zine closely, which meant that they missed significant parts of the content. These readers did not have the time I had for studying zines but is also possible that they did not have the capacity or commitment to receive what was articulated in the zine. My sense was that they were trying to be protective and respectful, responding to the rawness of the visual communication and the uncertainty about

sharing the zine that was suggested/communicated by the padlock, chain and bandages. These readers met her in the zine sharing session so hadn't been party to the earlier conversations Bex had with me about her zine. These participants' discomfort at reading Bex's zine might have been reduced if they hadn't been reading it in Bex's presence. I would certainly not have needed as much encouragement to actively engage with the zine if I had been reading it on my own. This is because I wouldn't have been concerned about how my reading her zine might affect Bex. The context in which these zines were read has some similarities to when zines are read in the presence of other zinesters at zine fairs but is very different from when zinesters post their zines to readers. If the unusual structure and sculptural qualities put off capable and committed readers the use of these elements to test readers would appear to be an ineffective strategy to evaluate potential audiences.

Kaz

Kaz's zine is a concertina folded zine made from multiple pieces of paper. As such it doesn't really stay closed, and the contents are not entirely contained within the basic structure of the zine. For example, a jack-in-the-box on a spring made from shiny pink foil pokes out of the top of the zine and springs out when the page it's included on is opened (image 7.25), and images fold out of another page (image 7.26).



7.25 Page from Kaz's zine

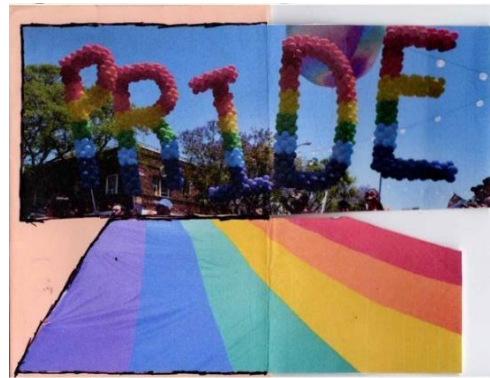


Image 7.26 Page from Kaz's zine

Both participants who read and commented on Kaz's zine described her use of sculptural qualities as impactful. Bex commented that *"It's like the zine's a jack-in-the-box"* whilst Diane described it as "fun". When I read Kaz's zine, I felt the sculptural elements communicated a sense of urgency, inevitability and joy. The concertina fold and the jack-in-the-box all gave me a sense that the joy was inevitable and uncontainable. This was added to by Kaz's use of multiple colours of paper. Without the accompanying text I would have not understood that Kaz's zine was about the process of coming out and with, but without the sculptural elements I wouldn't have gained an understanding of the sense of urgency, inevitability and joy. If this had been articulated just in words, pictures or even a combination of these, I don't think I would have understood it as well. I might have understood it theoretically, but I wouldn't have gained the visceral understanding that I gained from Kaz's use of sculptural elements.

Although very little has been written about the sculptural elements of zines, Bannister (2020) has written about Rumi Clinton's comic *Mental: Boxed In* (2017) which is presented in the form of a box containing coiled paper. Bannister (2020) describes how opening Clinton's comic is like a structural metaphor for exploring mental health. I understand this as meaning the act of opening the box and everything bursting out mimics, and stands in for, the way in which

emotions and thoughts feel very difficult to contain when we are struggling with our mental health. The way Bannister describes this comic is similar to the way in which Kaz indicates a sense of uncontainability through her use of a structure that bursts open and a jack-in-the-box that bursts out. Although as described in chapter 5, zines can work as containers, it would appear that some experiences like sexuality/joy at coming out, and in Clinton's case mental health, are difficult to contain. Notably survivor Dina Poursanidou's zine about her experience of physical restraint is on A2 card, which she did not restrict through folding or binding. She writes that she created her zine in this way because she felt that the restriction and constraint of a standard A5, A6 or A7 booklet "would symbolically re-create [her] traumatic experience of physical restraint" (Poursanidou, 2025).²⁹

Essentially, Kaz like Bex engages her readers through the use of sculptural metaphor. The uncontainability of Kaz's zine serves as a metaphor for her urgent need to come out, whilst the shiny love heart paper might be seen as a metaphor for her joy at coming out. Similarly, Bex's use of a confusing structure served as a metaphor for Bex's feelings of disorientation and the difficulty of navigating her experience, and her use of other sculptural elements served as metaphors for different aspects of her experience, e.g. fragmentation, constraint and absence.

In summary, whilst all the participants and I emotionally responded to the sculptural elements and structures when we read these zines, we didn't act on these responses in the same way.

The difference in our actions may be due to the context in which the zines were shared and read, including conversations between the zinester and the readers.

²⁹ You could argue Dina's zine is not a zine because it is not folded or bound into a booklet form, but Dina refers to it as a zine, additionally zines have a variety of physical structures and it is not uncommon for zines to open out to have a single image or poster on one side, so the line between booklet and not can be blurry.

Creative objects

All but one of the zines that participants shared with me, or made as part of this study, were physical zines printed on paper. Experienced zinester Annie sent me one zine in digital format which she has since turned into a physical zine. Annie said that it was important to her that her zines were a physical object and explained that she shares the zine instead of sharing herself. What I think she meant was that the zine became the focus, and this created some degree of separation or distance between her and the content she was sharing. Similarly, one of the survivors I introduced to zine-making (Bex) said that when she shared her zine with her colleague, she was sharing what she had made, the creative object, not the experience that the zine was about. As Bex used her zine to share an experience that she described as taboo, the focus on her zine as a creative object may have helped make this possible.

Similarly, I have found that I have shared things in zines that I wouldn't have shared otherwise, and this partly because I felt that the zine, as an object, created a different focus. For example, if people questioned why I was communicating a taboo topic I could deny that and say I was just sharing a creative object with them. For example, I recently sent a zine to someone about losing a friend to suicide. I felt able to share it because, although the topic felt taboo, the zine is a creative object, and the focus was on that. In the note I sent with the zine I emphasised the focus on the creativity of the object itself, like the way I had used the image of a lighthouse on one side and a series of rocks on the other side. When I shared this zine with others, readers responded both to the content and to the zine as a (creative) object, but I felt that the ability to focus on the creative object protected me from the social cost and shame of communicating something that felt taboo. You don't have to be in the same physical space as a person who is reading your zine. Therefore, using zines as creative objects gives survivors the opportunity to create a sense of distance between ourselves and what we feel able to share via our zines (see image 7.27).



Image 7.27 Using a zines to distance self from testimony

The way that some survivor zinesters use zines as a creative object to create distance between themselves, the zine content and readers, doesn't necessarily contradict what I said in previous chapters about how the material and handmade qualities of zines can create a sense of intimacy and connection between zinesters and zine readers. I suggest that zines can do both, depending on the zine and the context. I'm not aware of any literature about people using zines to distance themselves from what they're sharing. However, there is literature that indicates zinesters share very sensitive personal information via zines, including accounts of sexual violence (Fortin, 2022); experiences of sexual abuse and self-harm (Schilt, 2003). and experiences of menstruation, and (mental) illness (Nijsten, 2017). There is also literature about how focusing on art in therapeutic settings can create a sense of distance which enables people to share things they might have felt unable to otherwise. For example, Dalley *et al.* (1993) refers to the voice of the art being separate to the voice of the client; Haeyen (2018) writes that "art therapy allows clients to look at themselves and their own product from a distance" (p.17); Johnson (1987) explores how pictures can create a sense of emotional distance because pictures are concrete and external to the self; and as I mentioned in chapter 5 Clacherty (2024) has described how a zine can work as a container, providing a sense of separation between the

contents and the creator. Whilst zine-making is not a form of (art) therapy, and none of these survivors' shared zines with therapists for the purpose of therapy, some survivors use the material quality of zines to enable them to share things they wouldn't share otherwise.

Summary

Survivors use different zine qualities, in different ways and to various effects, to facilitate their process of sharing testimony. Visual qualities, unusual structures and sculptural elements were used to help communicate some aspects of survivors' experiences. Different aspects of experience were better communicated using different zine qualities. Visual qualities, unusual structures and sculptural elements sometimes helped readers to gain a visceral and emotional understanding of survivor's subjective experience whereas using multiple zine qualities (e.g. visual and text) helped readers gain more multifaceted understandings of survivor experience.

Sculptural elements and unusual structures in survivors' zines can prompt emotional and visceral responses in some readers. Some survivor zinesters use sculptural elements and unusual structures with this intention in mind. Sculptural elements and unusual structures can make readers feel the understanding they gained from reading the zines is less theoretical and abstract and more felt and embodied. The understanding might be described as the type of understanding someone might gain when doing a practical learning activity instead of reading a book. This is significant because this may be a way for us to better understand another person's experience as they experience it. In other words, it is an effective way to communicate subjective experience.

Although sculptural elements and unusual structures can prompt emotional and visceral responses, readers didn't always consciously link these to the content of the zine and so may not gain the contextual understanding that zinesters may have intended. In other words, they might get a sense of the zinesters' experience, without being able to relate this to what the experience was. Essentially the unusual structures might convey feelings but are not always

successful in conveying an understanding of what might be important in the content (or the context) for the feelings evoked. This doesn't undermine the argument that sculptural elements and unusual structures might be considered interpretive resources that are part of an epistemic system focused on understanding subjective experience. For example, needing text and image alongside sculptural elements to articulate and share an experience is no different to needing multiple concepts to articulate and share an experience, or indeed using multiple diagnoses to try and capture and communicate a person's mental health difficulties.

One survivor zinester felt that their use of sculptural elements and unusual structures might be a good way to test the commitment of her readers to receive her testimony. Dotson (2011) suggests that people considering sharing their experiential knowledge with others evaluate and make judgments about the audience's capacity and commitment to receive the knowledge they want to share. Dotson (2011) links the need to do this with testimonial smothering, where people don't share testimony because they evaluate it as too risky.

Whilst using sculptural elements and unusual structures to test readers commitment might effectively 'weed out' readers who aren't committed to understanding survivor knowledge, it can also give readers the message that they don't want to share the information with them. In other words, it might not be an effective way to find an audience who is capable and committed to receive testimony. Indeed, some readers didn't actively engage with the zine in which sculptural elements and unusual structures had been used to challenge readers possibly because they were trying to be respectful and unintrusive towards the zinester. If readers think barriers have been created because a survivor doesn't want to share the information with them, the information the reader shares may not be received, despite the readers being competent and committed to receive it. In other words, it might mean that competent and willing readers don't receive the testimony that survivors would like them to receive.

Survivors' use of unusual structures and sculptural elements to test readers commitment, raises questions about how survivors might effectively evaluate potential audiences. Dotson (2011) argues that testifiers evaluate audiences' willingness and ability to receive testimony and consider how risky sharing testimony might be. However, Dotson doesn't write about the processes of evaluation testifiers might use. This is important given that we know survivors 'smother' testimony when they have evaluated it as too risky to share with an audience.

The focus on sharing a creative object can make it easier for some survivors to share experiences. For some survivors it makes it possible to share issues, ideas and experiences they(we) see as taboo. This is because it creates distance between the survivor and the content/testimony they(we) are sharing, and the focus can be on the creative object.

In the last three chapters I have focused on how zine qualities relate to what survivors can articulate and share. In the next two chapters I write about the context in which survivors created and shared zines and how this relates to what they articulate and share.

Freedom, control and audience choice

The previous three chapters explored how the qualities of zines and zine-making can enable survivors to reflect on, articulate and communicate experience. This chapter focuses on the sense of freedom and control that zine-making offered some survivors, including freedom about what was expressed and who it was expressed to. First, I address the freedom and control over content, and examine a specific example of this, the freedom to be critical and angry. I then suggest that agency relates to the specific contexts in which zines are made by survivors, and I draw out the differences between survivors who are experienced zine-makers and those who I invited into this activity. The second half of this chapter explores experienced and novice zinesters' choices about who to share their zines with, and to what purpose/effect. This includes analysis of how some experienced survivor zinesters felt able to collaborate and share common concerns safely, through making and/or sharing their zines with/in chosen audiences and chosen communities.

As outlined in chapter 1, MH professionals decide who can share what knowledge, when, where and how; survivors have very little control over how our knowledge and understandings are recorded or (mis)used; and survivors sometimes don't share testimony they perceive will not be welcomed by professionals. Unwelcome testimony includes that which professionals might perceive as criticising or challenging them or their position. In contrast, as zines are self-published, and often shared within (alternative) communities, they may offer a context in which survivors can experience greater control, and thus potentially challenge aspects of epistemic injustice.

So, whilst previous chapters explored the creative, visual, handmade, non-linear and sculptural qualities of the zines themselves, this chapter focuses on the contexts in which zines are made, shared and viewed through the lens of power and agency. Again, I draw on interviews with

participants and their zines; the zine-making and sharing sessions; and my own experience of creating and sharing zines.



Image 8.1 Resources, freedom and choice

Freedom and control over content

This section outlines the sense of liberation and control that experienced zinesters described in relation to their zine-making. Subsections explore the freedom to be critical and angry, and then how agency relates to contexts for experienced and novice zinesters.

Some experienced survivor zine makers related zine-making to feeling or being unconstrained. For example, Luna said making zines was “*liberating*” because she was “*able to do things on my own terms*” and was not subject to external “*boundaries and rules*”, whilst Rin, Sophie, Annie, Lisa and Kira all used the word “*freedom*” in relation to their experiences of making zines. For example, Kira said “*There is a feeling of freedom that I don't have with any other kind of media that I produce. There is a feeling...that this is...a space that I can really and truly be my whole authentic self*”. Sophie also emphatically described feeling unconstrained whilst making her zines, said “*you feel like nobody's trying to shut you down, nobody's trying to shut you up.*”

Some experienced zinesters described having control over the content of their zines when making them. Kira said, “*nothing was off limits*”, Annie said “*You can really put what you want*

[into zines]”, Rin said “*you could literally just write whatever you wanted*”, Lisa said “*I pretty much put everything in*”, and Kirsty said, “*people produce what they’re interested in*”.

Annie and LJ spoke about being able to control the process as well as the content. Speaking about making and distributing zines, Annie said, “*There’s a lot of control you know*” and LJ said they often returned to making zines because it was a space where they could control what they made and how:

“I still come back to making zines because there is that like control over them because you’re not like facing an editorial hand and so you’re making decisions”

Similarly, in her blogpost on the MadZines website, Rachel Rowan Olive wrote:

“Some things I have to say, I can only say via zines: I do display my work in curated spaces, and I write for publications, but that often involves making decisions on what to include based on criteria I either don’t understand or don’t agree with. I literally make the spaces inside my zines with my hands, and that means I get to decide what goes on those pages.” (Rowan Olive, 2021)

The control over content in zine-making was contrasted with lack of control in other forms of publishing. LJ contrasted the control they had making and sharing zines with their experiences of having a book published and Luna contrasted her ability to control the content of her zines with the way in which a publisher had wanted to frame her ideas and experiences in a particular way. Luna further explained how she walked away from a book publishing contact so she could do things on her own terms. She did this because she felt that the publishers weren’t “*mad friendly*”, “*safe*” or “*accessible*” to her as a survivor. Therefore, for both Luna and LJ, being able to self-publish zines was linked with being in control of the content.

All the experienced zinesters, apart from Sophie and Dolly, explicitly related zine-making and sharing to not being subject to external control. Rin illustrated this beautifully when they said:

“That’s kind of my main motivation behind why I make zines... that I don’t need to ask for anyone’s permission... You don’t need to wait for permission to say what you have to say, and I guess that’s kind of my main motivation behind why I make zines”.



Image 8.2 Freedom, control and self-publishing

These descriptions of freedom and control over what they communicate in/via zines, contrasts with literature suggesting that MH system survivors are often reliant on being given permission or invited by MH professionals to share knowledge in the MH system (Rose and Kalathil, 2019; Peck *et al.*, 2002; Grim *et al.*, 2019; Tobin *et al.*, 2002). Essentially, in the MH system, the areas of concern and the parameters for what can be known tends to be preset by MH professionals, whereas experienced zinesters didn’t experience this when they made their zines. Whilst most survivors didn’t explicitly compare the sense of freedom they experienced in zines with their experiences of the MH system, I make this comparison on the basis that some survivors did say they could include criticisms and anger in zines that they wouldn’t articulate and share in the mental health system. When making their zines, experienced zinesters felt able to exercise agency in relation to the content of their zines and able to set the agenda to articulate what was important to them.

The sense of freedom that experienced survivor zinesters described in relation to content could be seen as contrasting with the sense of containment I describe in chapter 5. However, I

suggest that the sense of freedom described here is the result of a lack of externally imposed boundaries, whereas the sense of containment is provided by self-created flexible boundaries. In addition, the boundaries I describe in chapter 5 related to the amount/size of content; the length of time a person might spend creating a zine; and the number of people who might read it. These self-imposed boundaries did not limit *what* the content could be. In the context of the zine community, where there was an absence of structural power imbalances and where zines are self-published, experienced survivor zinesters felt free to choose the content of their zines. As an example, some experienced survivor zinesters expressed this agency via making (and sharing) critical and angry zines.

Freedom to be critical and angry

This section outlines how some experienced survivors made and shared zines in which they criticised, satirised and/or expressed anger at MH professionals or the MH system. I also note that creating critical, satirical and angry zines can be a way for survivors to resist becoming habituated to MH services.

Experienced survivor zinesters Annie, Luna, LJ, Dolly and Rin made and shared zines which criticised and/or satirised the MH system, essentially sharing testimony they thought would be unwelcome in the MH system. For example, Annie's *Psych Trauma* zine is a critical account and description of her negative experiences in services and her *Good Patient* zine is about difficulties accessing specific treatment in addiction services; Luna Tic's *Crisis Leaflet* zine and her *Mad Aphorisms* zine are both critical of, and satirise, services; LJ described sharing a zine in which they criticised the practice of a specific psychiatrist; Dolly spoke about making zines satirising MH services; and Rin's *Shitfulness* zine satirises the use of mindfulness in services. Satire is essentially criticism in which humour is used to undermine a person or idea that is seen as having more status or a higher position than they should have. Dolly spoke about "the power of making people laugh" and essentially described satire as a way to reclaim power.

Rin was able to make and share a zine which they described as “very much me taking the piss out of mindfulness”, a critique they felt unable to articulate in the MH system. Rin said although they think mindfulness “*is a bullshit thing that has been created to dismiss people*”, when mental health professionals suggest they try mindfulness they feel like they have to say “*mmm, what a good idea ... Yeah, I can try that*”. Rin said there was an expectation in services that service users must not “*make fun*” of things like mindfulness. Like Rin, I am critical of the MH system in many of my zines and use them to challenge the power and position of MH professionals where I feel unable to do this within the MH system.

Annie described zines as a space in which people could share anger and Rin, Dolly, Sophie, LJ and Kira all described making zines in order to articulate and share their anger. Annie said “*when I first started to read zines, I was a little put off because ... I was a bit like, oh these people are angry*”. She also said, “*I think I have heard that from a couple of people, that feedback that zines are too intense and angry*”. Sophie said, “*I think zines are quite good when you're angry*” and Kira described finding in the zine community an audience with whom she could share “*my anger -- dare I say, my rage -- at the current state of the world, and at the state of my own mental health*”. Using zines to articulate and share anger may be especially important to survivors because, by virtue of receiving psych diagnoses, our anger (and other emotions) may be pathologised and not taken seriously. Thus, it is especially difficult for survivors to be angry as it risks this being used to re-confirm our madness.

The anger in Rin, Dolly and LJ's zines included anger at service's treatment of survivors. Rin said their zines *How to be an acceptable autistic activist*, *Ways to redeem your autism* and *Shitfulness* were all motivated by anger; Dolly described her *Piss off with your pain you peasant's* zine as being motivated by anger at National Institute for Health Care and Excellence's lack of appreciation of the complex relationship between physical and emotional pain, and LJ described making an angry zine about a meeting with a psychiatrist. LJ said:

"I'd had like a really shitty meeting with a psychiatrist, and I was fuming, like pure raging, and I was just like 'right then I'm just going to fucking make a zine'. And it's dedicated to him. So, the front of that one, says 'to Doctor Hayward and all the other psychiatrists fuck off'. I was channelling some rage then."

Experienced survivor zinesters' accounts of being able to share anger in/via zines contrasted with what they said about being able to be angry in the MH system. For example, Luna described declarations of survivor anger being "*politely ignored*" by professionals at a MH conference, and Rin said there was an expectation in services that service users must not use an "*angry*" or "*snarky*" tone and spoke about there being a cost to articulating anger in mental health services.

Like Luna and Rin, I have found that survivor anger is unwelcome in the MH system. I have found that if I want to be heard in the MH system as a survivor, I am expected to speak in a professional tone devoid of strong emotions, especially anger. When I have spoken about feeling angry as a survivor in the MH system, I have worried that it would be assumed to be related to, or even a symptom of, mental illness. For example, when doing some work with survivors in dialogue with professionals about the use of physical restraint in hospitals, it seemed clear to me that professionals' defensiveness, feelings of vulnerability and anger were seen as reasonable and acceptable whilst any sign of survivor emotions were seen as pathological, despite evidence that physical restraint can be degrading (Gelkopf *et al.*, 2009); traumatising (Bonner *et al.*, 2002; Knowles *et al.*, 2015); and negatively impact survivors (Evans and Fitzgerald, 2002). My sense was that the unwillingness, or inability, to hear the anger of survivors in the MH system, prevented the extent of the harm being fully understood.

As I outlined in my theory chapter, Bailey (2018) wrote about the relationship between tone management and epistemic injustice. She argued that anger is entwined with knowledge of injustice and that preventing the sharing of anger can result in people being unable to share

experiences of injustice. Bailey (2018) further argued that “Silencing anger exacerbates the harms of epistemic injustices” creating what she describes as “anger-silencing spirals” (p.96-97). In other words, as anger is a sign of injustice, silencing it can magnify the injustice and the accompanying anger, thus creating a vicious spiral effect. That survivors felt able to create and share anger in their zines suggests that the context in which these zines were produced and shared provided opportunities for survivors to exit, or at least avoid, the anger silencing spirals that Bailey describes.

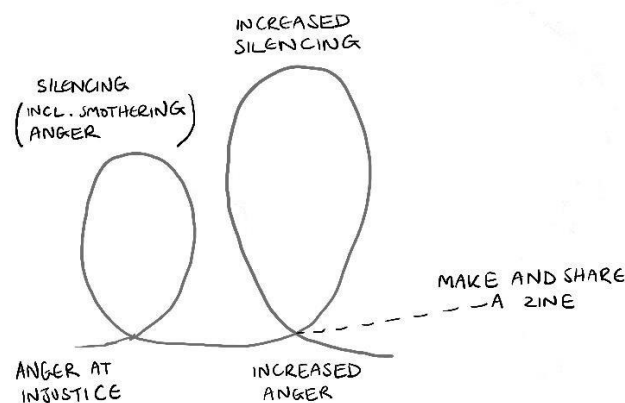


Image 8.3 Exiting the anger silencing spiral

Notably, several experienced zinesters specifically described making zines in response to feeling angry about being silenced. Drawing on Bailey, we might suggest that their anger contained their knowledge of epistemic injustice. For example, Sophie’s anger was entwined with her experience of being silenced, and her sense of injustice about this, and she was able to articulate and share this through her zine:

“I felt like everyone in my whole life had been saying that, just been like ‘stop talking about this’, or ‘be quiet’ or ‘shut up’ and it was, I just got to the point where I was like “no I will not”. So, I made the zine”.

Similarly, Annie linked making zines with her increased awareness of the silencing of marginalised people: *“there's been systematic silencing of these voices and complete lack of ability to hear what they have to say.”*

Similarly, Rin described making a zine as a way of holding on to the knowledge their anger contains. Effectively, they seemed to make zines in order to protect themselves from internalising what Bailey (ibid) might refer to as the ‘tone management’ of MH systems:

“Because I don't want to become one of these mellow people, who because they've had to censor themselves because of work because of the environment they're in, their opinions end up being mellow.”

Rin could be described as resisting the MH system's beliefs and expectations, engaging in an affective process of reflection and defining concerns despite social conditioning which requires survivors not to be angry about the ways they are treated in the MH system. It is significant that both experienced zinesters and I were able to create zines in which we expressed anger and criticism of the MH system because this involves stepping away from and/or rejecting structural conditioning which can be internalised and shape the ways in which we can define our concerns and decide on actions. Indeed, as I outlined in chapter 2, some survivors spend many years in the MH system and, in these cases, it is difficult to imagine how we wouldn't internalise its norms and expectations, including the ways in which our epistemic ability is perceived as limited; our criticisms perceived as unwarranted and unconstructive; and our anger (and other emotions), by virtue of receiving psych diagnoses perceived as pathological (Grim *et al.*, 2019; Crichton *et al.*, 2017; Sanati and Kyrtatsous, 2015; Lindow, 1999; Omeni *et al.*, 2014, Felton and Stickley, 2004). By making angry zines, survivors can be said to be rejecting the idea that anger is merely a symptom of a disorder and that our criticisms are unwarranted and unconstructive. We could also argue that it involves valuing ourselves as epistemic agents.

Experienced survivor zinesters seem to feel able to criticise and satirise the mental health system and express anger in their zines because they were aware of, and had access to, a community in which it was acceptable to do this. As noted in chapter 2, the use of zines to communicate anger has been commented on by other researchers (Licona, 2012; Cofield, 2018; Hwang, 2022). In addition, whilst criticisms of MH systems and professionals might be unwelcome in the MH system, people in the zine community don't have the same investment in protecting the status quo of the MH system, they are not being criticised and their position is not being called into question.

Agency within Contexts

What experienced zinesters said about zine-making differed from how the survivors I introduced to zine-making described it. I suggest that there is something important about the different contexts in which their zines were made, so I explore this in the following two sub-sections looking at the differences between what experienced survivor zinesters and novice survivor zinesters said and did.

Experienced survivor zinesters zine-making context

In this section I show how the freedom and control that experienced zine makers described, may relate to the context in which they were made. For example, they tended to make their zines on their own, away from anyone who might distract them or curtail the process in any way; they weren't reliant on others to provide resources; and they made their zines with the zine community in mind.

Although LJ and Kirsty were particularly embedded in contemporary zine cultures and spoke about facilitating zine workshops and making zines at zine fairs, along with all the experienced zinesters who spoke about where they made their zines, they described making (most of) their zines at home, usually on their own. Notably, LJ also said that when they ran zine workshops, they helped people get to know the medium but didn't try and get people to make zines together. They said, "*most people from my experience like to go off and spend some time*

thinking about things and processing". Significantly, Sophie said she didn't like making zines in workshops because workshop facilitators might require her to make zines differently to how she chose to, and she dealt with this by not attending zine-making workshops.

Survivors can articulate their thoughts in zines without being reliant on other people to provide them with the resources with which to do this. Lisa and Sophie noted that zines can be made with just a pen and paper, and Sophie described this as taking a sense of pressure and expectation off the zine-making process. Similarly, Dolly spoke about making her first zines just for herself, on her own at home with whatever material she had to hand.

"I became psychotic at, really severely psychotic, at 14. And really didn't leave my bedroom until I was about 30. So, I was actually making zines out of um, whatever material was at hand. But they didn't leave the room, it was for me, just because I wanted to do them."

In a similar way, part of what enables me to have a sense of freedom and control over what I can articulate in my zines is making them away from other people, in my own home using resources of my own and in my own time. It is about the specific circumstances in which my zines are made, and the fact that my zine-making wasn't reliant on other people because they could be made with resources I could access, own and control.

Sometimes my zines are not just about making sense of my experience for myself. When this is the case my sense of freedom and control is also related to who I imagine I might share my zines with and whether I am able to imagine an audience who might understand my experiences. When I don't think anybody will be open to receiving my account of my experience, or my understanding of it, then I might not spend time and energy creating a zine about it.

All the experienced survivor zinesters I interviewed spoke about a zine "*community*". They often used the terms zines and zine community interchangeably, which fits with how zine scholars

have described zines as a community space like a clubhouse (Duncombe, 2017) or an embodied community (Piepmeier, 2009). The community they referred to seemed to be the people who participate in zine culture, i.e. people who read, make and swap zines and people who attend zine fairs. In other words, it might be described as an 'imagined community' or a community of mutual regard. Anderson (2006) used the term imagined community to describe when people have similar interests and perceive themselves as part of the same group. He writes that in an imagined community members "will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion." (p.6). He further links imagined communities to print media, noting that when people read newspapers, for example, they are "well aware" this process of reading "is being replicated simultaneously by... others of whose existence" they are "confident yet whose identity" they haven't "the slightest notion" (Anderson, 2006, p.35). Piepmeier (2008) highlights that the zine community/community of zines does not rely on sameness, but rather "variety, social differentiation without exclusion, and a heterogeneous public" (p.215) Piepmeier (2008) draws on Young's (1990) idea of 'communities of mutual regard' which share the warmth that can be present in face-to-face relationships, but which do not try and impose a strong sense of mutual identification, that would likely reproduce exclusions.

Some experienced survivors zinesters said one of the reasons they chose to make and share zines was because of the welcome, solidarity, and belonging they felt in the zine community. Kirsty said, "*For me it's a community I've felt very welcomed in*"; Luna described it as a community she feels connected to; Annie spoke about a sense of "*solidarity*"; Sophie described it as a community in which people who are silenced elsewhere have "*a sense of belonging*" and linked this to a sense of solidarity and common purpose:

"We're in the same war, in the same, doing similar sort of things, wanting similar sorts of things, so that's a feeling of community, in a way."

These descriptions of solidarity, community and shared purpose between experienced zine makers and readers are in stark contrast with literature about the MH system which describes MH professionals as not welcoming survivor knowledge which they perceive to be challenging them or their position (Lindow, 1999; Omeni *et al.*, 2014; Felton and Stickley, 2004; Grim *et al.*, 2019).

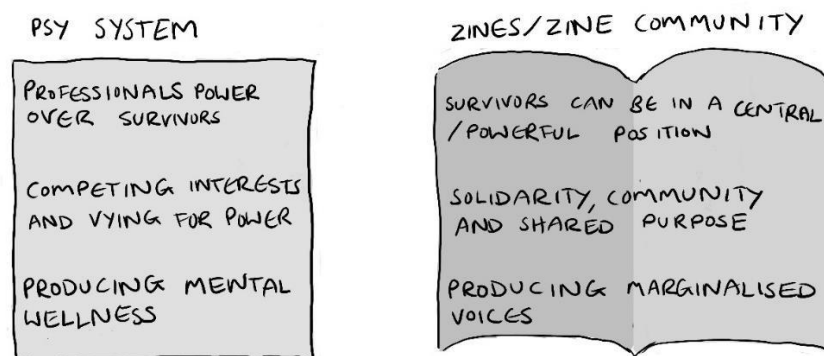


Image 8.4 Contexts

Significantly, none of the survivors spoke about MH professionals having power over what they could include in their zines. Rather, some experienced survivor zinesters felt they could take a central and powerful position in relation to the zines they make and and/or what they called the zine community.

Those experienced zinesters who described zines and zine communities as spaces for marginalised voices explained this in various ways. For example, Annie described zines as being *“a space that’s intrinsically there for marginalised voices”* whilst Mary described the zine community as being *“for people who might feel marginalised or might feel like they’re not heard, or they might feel like they are not understood”*. Mary also said *“that’s what I like a lot about zines is that anybody and everybody can have a voice if they if they want to. Especially people who might feel shut down or quiet.”*

Some experienced zinesters made contrasts between zine communities and other spaces. Annie, Kirsty and Rin explained that although they were in a marginalised position in other

spaces, they didn't feel that way in zines or the zine community. Kirsty said that as someone who has "*to some extent marginalised*" identities in mainstream culture, they didn't feel marginalised in the zine community. Similarly, Annie spoke of people who are marginalised elsewhere having a sense of power in relation to zines:

"I think when you look at zines, you don't feel like you are a marginal voice as much. You feel the power, you know the power in the margins".

Essentially, these survivors described being able to take a more central role/position in the zine community than in other spaces and, at least for Annie, this came with a sense of feeling empowered.

Experienced zine makers explicitly contrasted this with being disempowered within the MH system. For example, Rin said they didn't feel marginalised in the zine community in contrast to the MH system where "*You are not an equal, you know, you're very much not an equal*".

Like Rin, my experiences of power in zine-making contrast greatly with my experiences of the MH system. My experience of these different power dynamics shaped what I felt I could spend my time and energy reflecting on and articulating. As a service user in the MH system, I was acutely aware of being marginalised by the professionals I was relying on for treatment and often wasn't invited or allowed to express my thoughts and feelings. In addition, when I was asked to reflect on and articulate my thoughts in the MH system it was usually on topics that weren't important to me. For example, I was often asked/expected to spend my time and energy reflecting on how I thought a service might be best decorated or what name to give a service. In contrast, when I have made zines, I do so with an awareness that there is a community of people who are not in positions of power over me; who aren't concerned that I might try and undermine their position; and who are not going to use their position to try and shape what I spend my time and energy thinking about. I don't have the sense that people in the zine community are setting any agenda for my zines or shaping what I spend my time thinking

about. Even if this were the case, I wouldn't worry so much about what their agenda might be because they don't have the same power over me as MH professionals did when I was in services. In other words, my awareness of the power dynamics of the zine community enables me to set my own agenda, to freely choose what I spend my time reflecting on and articulating.

The following section explores the significance of the context in which the survivors I introduced to zine-making created their zines.

Introducing survivors to zine-making

The environment in which I introduced survivors to zine-making differed from the one in which experienced zinesters made their zines. The survivors I introduced to zine-making had all been invited to take part in zine-making through the mental health support they were accessing, where support staff issued invitations on my behalf and the zine-making sessions were all facilitated by me in the venues where they accessed support. Other than Bex, these novice zine makers had no knowledge of the zine community and found it difficult to imagine who they might share their finished zines with or how they might do this. Whilst they were making their zines, their imagined audience seemed to include me, people who worked in the organisation they accessed for support, and the people who might read my thesis.

When zines are made in workshops, at the request of a researcher, and/or in spaces that are connected to services, survivors may feel that they are not in a position of power and that they need permission to create (and share) zines on particular topics, or in particular ways. None of the survivors spoke about feeling disempowered, marginalised or at risk of harm when making zines as part of this research. However, even if they did feel this, they may not have felt able to tell me because I was in a relatively powerful position in this context and my presence or actions might have led to them feeling restricted. Notably, in this context none of them described the sense of freedom and control that the experienced survivor zinesters described. It's possible novice zinesters didn't describe a sense of freedom and control because they were

inexperienced at making zines, and didn't have extensive knowledge or confidence in relation to zine-making however I didn't get the sense that this was the case as they all seemed really comfortable with the creative process and using the resources provided.

Survivors' potential lack of freedom in this setting is illustrated by the fact that they all asked me what they could or should make their zine about. In other words, they saw me as setting the initial agenda and the parameters of what could be articulated and shared. Although I told them they could make their zine about anything, some of them appeared to think/feel that they should make zines on topics that they thought I might want. For example, when Diane first spoke about what she might make a zine about, she said she might make a zine about negative assumptions about her parenting ability on the basis of her mental health and when Kaz first spoke about what she might make a zine about she spoke about making a zine about how great the support group she attended was. In other words, it seemed that these participants initially perceived the agenda and the parameters about what could/should be included in their zines as having been set by me and my research topic (i.e. they thought it had to be related to mental health in some way).³⁰ Kaz's initial idea may have been based on what she thought the service she was accessing might want, although she may have just wanted to express her appreciation for the service, which she experienced as really helpful. My sense was that the person who ran the group she attended was really happy for Kaz to choose her topic, but Kaz's initial choice may still have been influenced by what she perceived the worker/service might want.

If survivors think they are expected to make a zine on a particular topic, this may limit their ability to use zine-making to reflect on and articulate their experiences, in their own way. It might also replicate the ways in which survivor knowledge is excluded from being shared in the

³⁰ Although they knew my research was about mental health, I stressed they could create zines about anything, as I wanted the participants in zine workshops to have the same sense of freedom described by experienced survivor zinesters. I didn't want to replicate the way that in the MH system the topics that survivors can share testimony about are curtailed by pre-set agendas (Rose and Kalathil 2019, Peck et al 2002, Grim et al 2019, Tobin et al 2002).

MH system through agenda setting (Rose and Kalathil, 2019; Peck *et al.*, 2002; Grim *et al.*, 2019; Tobin *et al.*, 2002) or through survivors deciding which testimony to share based on what they felt would be welcomed in the MH system, and what wouldn't result in their treatment being negatively altered (Grim *et al.*, 2019; Laugharne *et al.*, 2012).

When I reiterated at our next meeting that they could make a zine about anything they wanted to, both Kaz and Diane changed their minds, and this seemed to indicate an increased sense of freedom. Instead of trying to meet the perceived needs of my study by making zines about mental health services or the MH system, Kaz said she would make a zine about coming out and gender identity and Diane said she would make a zine about the barriers that children in care and care leavers face.

This situation reminded me of a previous experience where I had been given the task of consulting survivors about their experiences of services and the survivors in question told me that they wanted to share their experiences of the benefits system with me instead because this was the most pressing issue for them. In other words, it was a reminder of how important it is for survivors to have the opportunity to set the agenda because survivors concerns and priorities may differ from those of services or the MH system and from what services (or researchers) think will or should be a concern or priority for survivors.

Diane went on to make her zine about care leavers in the way she said she would like to. However, whilst Kaz made a zine about coming out it didn't include anything about gender identity. There are many reasons why Kaz might not have included anything about gender identity in her zine. For example, she may have felt it might risk her ability to continue to access the support she was receiving. When speaking about gender identity Kaz had described herself to me as masculine and the service she was accessing was a women-only service, so it is possible that Kaz may have worried that covering gender identity in her zine might have resulted in her not being able to continue to receive the support which she was finding really helpful. As

far as I was concerned, there was no expectation that participants share their zines with the organisation they were accessing for support (or even include them in my thesis). However, the context in which the zines were made affected who survivors imagined their audience could be and this in turn may have shaped what they felt able to articulate in their zines.

Workshops in the setting of services (and/or the context of a research study) may not provide survivors with an opportunity to critically reflect on experience. This is because workshop facilitators, services or staff in services might set (or at least be perceived as setting) the agenda and the parameters of what can be articulated. In this way, such workshops might echo the way in which agendas are set and perceived to be set by professionals in the mental health system. What's more, participants may fear that the service/support they receive could be altered depending on the content of their testimony. This echoes the idea that fears about negative changes to support may be linked to survivors editing or censoring the testimony they share with professionals in the MH system. In other words, workshops in these settings might be experienced as replicating some of the epistemic injustices within the MH system. For these reasons, the agency survivors were able to enact when I introduced them to zine-making may have been limited by the context in which I did this.

That the experienced survivor zinesters described a greater sense of freedom and control in relation to their zine-making in comparison to the novice zinesters, supports the idea that agency is shaped by the context in which zines are made. The way in which survivors' sense of freedom appears to be related to who they imagined their audience could be, highlights the importance of audiences. Therefore, in the following section I explore survivors' audience choices.

Evaluating and choosing audiences

Although it wasn't always clear at what point survivors chose their audiences, they all engaged in a process of evaluating potential audiences and then deciding who they would share their

zines with. Some survivors decided who they would share their zine with after they had made their zine, but others seemed to have made this decision before they made their zine or during the zine-making process. Therefore, in this section I describe ways in which experienced zinesters and zine workshop attendees in this study evaluated and chose audiences with whom they felt they could share the zines they had created. In the first subsection, I explore the audiences that experienced survivor zinesters chose, and in the second, the audience's novice zinesters chose. I then outline how these choices can be seen as strategies, in a subsection about survivors collaborating and sharing common concerns through making and sharing zines.

Experienced survivor zinesters' audience choices

Experienced survivor zinesters tended to choose readers they thought would understand and welcome their zines. This included choosing to share their zines in the zine community and/or other welcoming communities. Some experienced survivor zinesters also chose their audience because they perceived it as safer. Although some also shared their zines with audiences that they thought weren't welcoming, they didn't prioritize unwelcoming audiences.

All the experienced zinesters, except Dolly and Luna, chose to share their zines within the zine community. Lisa, Mary, Rin, LJ and Kirsty spoke about swapping, giving away or selling their zines at zine fairs. Mary and Rin told me they shared their zines with zine libraries, Annie and Lisa said they swapped zines with zinesters they'd met online, and Kirsty sold zines via a zine distro. Annie, Kira, and Lisa sold their zines via Etsy, where people from the zine community often buy and sell zines and which Annie described as "*full of zines*".

Some experienced survivor zinesters chose to share their zines in the zine community because they had an idea of whom readers in this community would be and they believed these readers would value their testimony. For example, Kirsty said, "*I guess I broadly know the demographic of people who are buying zines from zine distros*"; Lisa said, "*I think, with making zines, they are going to be read by a very specific community*" and LJ said "*I know who my normal distribution*

is...even though people I didn't know were buying the zines. it was still kind of a community that I knew. Like I knew which community I was distributing in." In addition, whilst speaking about selling her zines on Etsy, Annie said *"I am not worried someone will buy this and be like 'this is shit' because why would you buy it?"* In other words, she had an expectation that her testimony would be valued in the zine community.

Some experienced survivor zinesters noted that sharing in the zine community meant sharing with readers they expected to have similar perspectives or experiences to them. Sophie said of her zines *"the only people who would look at them, in my opinion, is people who felt the same as me"*; Lisa said, *"the people you do come into contact with are probably already singing from a similar hymn sheet!"* and Luna described there being *"a big crossover with like zinesters and the mad community"*.

Dolly and Luna spoke about sharing their zines in activist or survivor communities or with people who connected to these communities. For example, Luna, said she shares zines through the survivor activist group, Mad Covid, so they reach a *"Mental Health service user audience"* and people who have *"access to another network or a community who might be interested"* and she gave the example of people who are linked with people who are *"involved in mad activism or going through difficult time using services"*. Dolly describes sharing her zines in *"arts spaces and political spaces"*.

Like many of the experienced survivor zinesters describe, I expect that people who might read my zines will be likely to understand and welcome my testimony because there will not be a huge gap between their experiences and perspectives and my own. I chose to share some zines with the wider zine community and others with the section of the zine community that crosses over with the mad community or with individuals I know are survivors or have similar perspectives to me. Although having the zine community in mind helps me feel there could be a welcoming and understanding audience for my zine whilst I'm making it, I don't decide exactly

who to share my zine with until I've finished creating it. I work out the details of what I want to say through the process of creating the zine and so, until I've finished, I cannot decide who I think the best audience might be. I am generally comfortable sharing zines about mental health (and services) in the wider zine community because I believe readers in this community won't feel criticised and defensive when I criticise services and because I think generally they value subjective lived experience. However, if my zine is about mental health (and services) I tend to target readers I think have some experience of services, and/or have a similar (critical) perspective to mine, because I think they are most likely to understand. I might put my zine on Etsy to engage with a wider zine community, but I make a point of sending it to zine libraries that focus on mental health and zinesters that I know are also survivors and/or activists. I have discovered that when I share zines with readers who understand and welcome them, it feels like it increases my epistemic confidence.

Similarly, LJ shares their mental health related zines with the wider zine community and survivor communities they are connected with from their time in services. They say they do this because:

"I don't wanna have to articulate the intense frustration of being sectioned just to everyone. I don't want to have to give context. I don't want to have to provide that information, I can't be bothered...For me, I think the actual meaning of them and the depth of them comes more if you've had like experiences in services, or if you really understand some of that shared experience."

In other words, it is important to LJ that they are understood, and they believe having some experience in common can support their understanding and they choose their audience accordingly.

Some experienced zinesters contrasted their experiences of sharing zines in the zine community with their experience of the MH system, and their anticipated and actual experience

of sharing zines with MH professionals. For example, Rin said that although they thought MH professionals would benefit from reading zines, they expected professionals would be “defensive” that they didn’t “*know if they quite have got the stomach for it (laughs)*” and Rin didn’t describe sharing their zine with MH professionals in the MH system. In addition, Luna referred to MH professionals ignoring a zine about survivors’ anger. She described putting up a poster, which included the words “*too right, we’re mad*”, from her Mad Activism zine, directly behind her when she gave a speech as part of the Mad Covid group. Instead of commenting on this, Luna says the audience of MH professionals “*politely ignored*” it. Although Luna shared her zine with MH professionals in this way and she hoped that maybe there was the possibility that it might plant “a seed” in people’s heads “*that there is a different perspective*” from theirs, she emphasised that MH professionals were not the main audience for her zines.

In common with all the experienced survivor zinesters, I don’t choose MH professionals as the main audience for my zines. This is in part because I don’t want to waste my time and energy on audiences that I don’t think are capable or motivated to understand. Many of my zines criticise the MH system or describe things from a survivor perspective and, like Rin, I perceive MH professionals to be invested in defending themselves against criticism and so I won’t share these zines with them. I also don’t believe MH clinicians value subjective/lived experience, unlike the zine community.



Image 8.5 Audience choice

For some experienced survivor zinesters, their choice of audience was about opting into a space/dynamic in which they felt safe(r) to share the testimony they had created.

Other than Mary, who was concerned about the risk of her boss coming across her zines, none of the survivor zinesters felt that sharing their zines was risky. None of them said they were concerned that sharing their zines with the audiences they had chosen might result in negative changes to how they were treated in/by mental health services. Annie said because the zines are for marginalised voices they are a “safe space” for survivors to share testimony and Rin contrasted their experience of sharing zines with the zine community with the harm they believed would happen if they shared them in the MH system.

Some experienced survivor zinesters shared testimony in their zines that they felt would be too risky to share in the MH system and contrasted their experiences of sharing zines with how risky they felt it would be to share the same things in the MH system. For example, Rin made and shared a number of zines which they said were motivated by anger which criticised and satirised aspects of services. They contrasted their ability to do this with their experiences of/in the MH system.

Rin spoke about the vulnerability of survivors' position in the MH system *"It's like you've been given a seat at the table, but really it's kind of a half-broken stool"* and described having to smother testimony *"they should be able to hear us, full honesty, full blast. But because you know that's not how they gonna perceive it, then you have to censor yourself."* Rin said that in the MH system they felt they had to censor their angry and critical testimony in order not to be seen by professionals as *"not worth helping and all that kind of crap"* and because they were worried that, if they didn't censor their testimony, survivors would no longer be invited to meetings:

"You can't be too angry or just snarky, because then you're making it harder for the next person, because then. Then they might decide there's no point in involving people 'cause they just get mad at us and things like that"

Essentially Rin shared their angry and critical zines away from the MH system because they felt that sharing them in the MH system would risk their losing support as an individual and because of the risk of survivors collectively being excluded from having the opportunity to have a voice in the MH system at all.

Like Rin I have felt that there are some things I can safely share via zines that it has felt too risky to share in/with the MH system. I have made zines and shared zines in which I am critical of services and/or express anger at services because this doesn't feel likely to result in harm to me whereas I wouldn't share these in the MH system for fear that it would be used as evidence that I am mad, ungrateful and challenging professionals and I worry I might be punished for this. The risk of harm is about power dynamics and my position in relation to my readers. Unlike if I were to share in the MH system, none of the readers I chose to share my zines with were in a position to take resources away from me, to control whether I'm incarcerated, whether I receive treatment, what treatment I receive or whether I'm seen as mad. In other words, my audience choice is partly about reducing risk.



Image 8.6 reasons for and effect of audience choice

Novice zinester audience choices

In the previous section I described the audience choices made by experienced survivor zinesters. Here I outline novice zinesters' audience choices.

The survivors I introduced to zine-making all made their decision about who they wanted their audience to be after they had finished making their zines. The audience these survivors chose to share their zines with was similar to the audience chosen by experienced survivor zine makers, even though the content of their zines may have been moderated due to the context in which it was made. I had thought the survivors I introduced to zine-making might choose to share their zines with people in positions to change the systems they wrote about, or to share their zines via the zine fairs and distros etc that many experienced zinesters spoke of. However, when these survivors did share their zines, they chose to do so with other participants and people they knew in person whom they thought would be interested in and value the subjective lived experience they shared in their zines. I explained how they could share (or not share) their zines with whomever they chose, and one participant shared their zine only with me; one

shared it only with other zine makers; and the others shared them more widely. Those sharing more widely, still only did so with people they knew and/or who they didn't feel it was risky to share with. They chose to share with these audiences because they had experiences in common; because they wouldn't be harmed if the person didn't understand and value their testimony; or because the person had some understanding of the context and had previously demonstrated that they had some understanding of what the zine was about.

In sharing their zine with other survivor participants, they might be described as sharing their zine with peers, or at very least with people whom they had some experiences in common.

When we discussed the possibility of sharing with other participants Bex, Nicola, Diane and Kaz all were interested to see what other participants had made and thought that other participants might also be interested in their zines. Bex also highlighted how sharing her zine with other participants didn't put her at risk of harm. Bex said of the participants she shared her zine with *"it wouldn't matter if they didn't get it"*.

Outside of other participants, novice survivor zinesters chose their audience depending on whether they thought they would understand and value the content of their zine. In addition to sharing their zines with other participants, Bex shared her zine with a colleague and with a group of people who were hoping to put on an exhibition about mental health and using art to externalise experience. Kaz told me that in addition to me and other participants she had shared her zine with the facilitator of the queer support group and a colleague and Nicola planned to share it with people in her life, including her partner, family and friends. Bex said she thought she might share her zine with her colleague as she had been talking to her about her zine and they had expressed interest in reading it. She also said her colleague seemed really nice and felt like they might understand. Although the people at the meeting about having an exhibition about externalising mental health difficulties didn't know Bex personally, or the context in which she had made her zine, Bex felt they would probably understand as they had

understanding and experience of struggling with mental health and experience of using art to externalize this experience. Kaz told me she had shared her zine with the support group facilitator and a colleague because she trusted them to understand and value her zine because they knew something about the context of her experiences described in the zine and because they had previously demonstrated they were interested in and valued her perspective and experience in relation to homophobia and coming out (the topic of her zine). Similarly, Nicola told me the people she planned to share her zine with were all people who had some understanding of her context and specifically some understanding of the topic she had made her zine about.

Therefore, although novice zinesters didn't share their zines in the zine community, their audience shared qualities with the audience experienced zinesters described. That is, it consisted of people with whom they had experiences in common and people they knew and expected to understand the testimony shared in their zine. Other than Bex, they didn't want to share their zines with people or systems/organisations that they wrote about in their zines. Whilst Bex tried to share her zine with people in the MH system, she was not able to. I tried to facilitate this sharing but received no response at all, despite my previous role and extensive experience facilitating survivor involvement in this area. Notably Bex said that she had expected this to be the response of the MH system and Diane said she didn't want to share her zine about care with care organisations because she didn't think they would be interested.

Collaboration and audience choice

Here I outline the ways in which community/audience choice was a strategy. Firstly, as a way in which survivors could create and share unsmothered testimony, then as a way in which survivors collaborated and shared common concerns, finally as a protective strategy.

Choosing to share zines in safe(r) dynamics and with a welcoming and understanding audience can enable survivors to share testimony we feel is unwelcome elsewhere, including testimony

we might feel we have to smother in other settings. As I outlined in chapter 2, Dotson (2011) argues that people evaluate whether potential audiences might be willing and able to hear testimony, and that when audiences are perceived to be lacking this causes people to 'smother' testimony which might otherwise have been shared with that audience (Dotson 2011).

Dotson (2011) also suggests that testimonial smothering is likely to occur where audiences' failure to welcome and understand testimony might pose risk of harm. In other words, it is related to the power dynamics between the audience and the testifier. Dotson notes that harm is related to context and "ignorance that is perfectly benign in one epistemic agent, given a certain social location and power level, would be pernicious in another epistemic agent" (Dotson, 2011, p.239). In this way Dotson (2011) can help explain why survivors chose to share their zines in a community they described as being absent of the deep power imbalances that are present in the MH system.

As Dotson (2011) notes, testimonial smothering is coerced silencing. By opting into a safe(r) dynamic, survivors were avoiding being coerced into smothering testimony; although this also meant they were unlikely to directly influence a wider audience. Whilst sharing with welcoming and understanding audiences might limit survivors' ability to have wider influence, I suggest that it may enable survivors to collaborate and share common concerns, which might in turn be a step towards achieving wider influence.

Survivors who want to be able to collaborate with others who value our epistemic contributions may strategically choose and prioritise audiences/communities we expect to understand and welcome our testimony. Sharing zines was described by experienced survivor zinesters Luna, LJ and Dolly as a social process through which they could pool their knowledge, collaboratively reflect, and identify (people with) common concerns. This can be understood as process of social reflexivity. Archer (2003,2007) writes about 'reflexivity' as the process through which individuals consciously and intentionally reflect on their own experiences and chose how to

relate to society, define concerns or goals, and decide on actions. However, her account has been criticised for not recognising that reflexivity can be a social interactive process and not acknowledging the importance of discourse (Caetano 2014). Although the process of reflexivity is social or collaborative, the concerns, goals or actions arrived at may be individual or shared. So, I use the term social reflexivity to describe a social or collaborative process of reflecting on experiences to identify and define individual or shared concerns, goals and relevant actions.

Luna described how sharing the zines she had made as an individual could result in audience engagement and be part of a process of collaborative reflection:

“Even when it's just me on my own putting my experiences and stuff out there I find that resonates with other people and I tend to then get responses from people of like: this this totally rings true for me, or I've had a really similar experience. Or, I have exactly that feeling as well. So, it's a ... kind of collaborative reflection.”

Luna thought that sharing her zines might be a way to develop solidarity and identify shared concerns. Luna described sharing zines with other survivors, people who are carers for mad activists, and people who understood disability justice but who didn't know about the mad movement with this purpose in mind. Luna described this as a process of sharing zines with “allies who don't know they're allies yet”. She said sometimes she shares zine with people:

“because I think that they'll be receptive to the ideas, they might be an activist anyway, or they might understand disability justice but not really know about the mad movement ... Sometimes it's because they have like access to another network or a community who might be interested.”

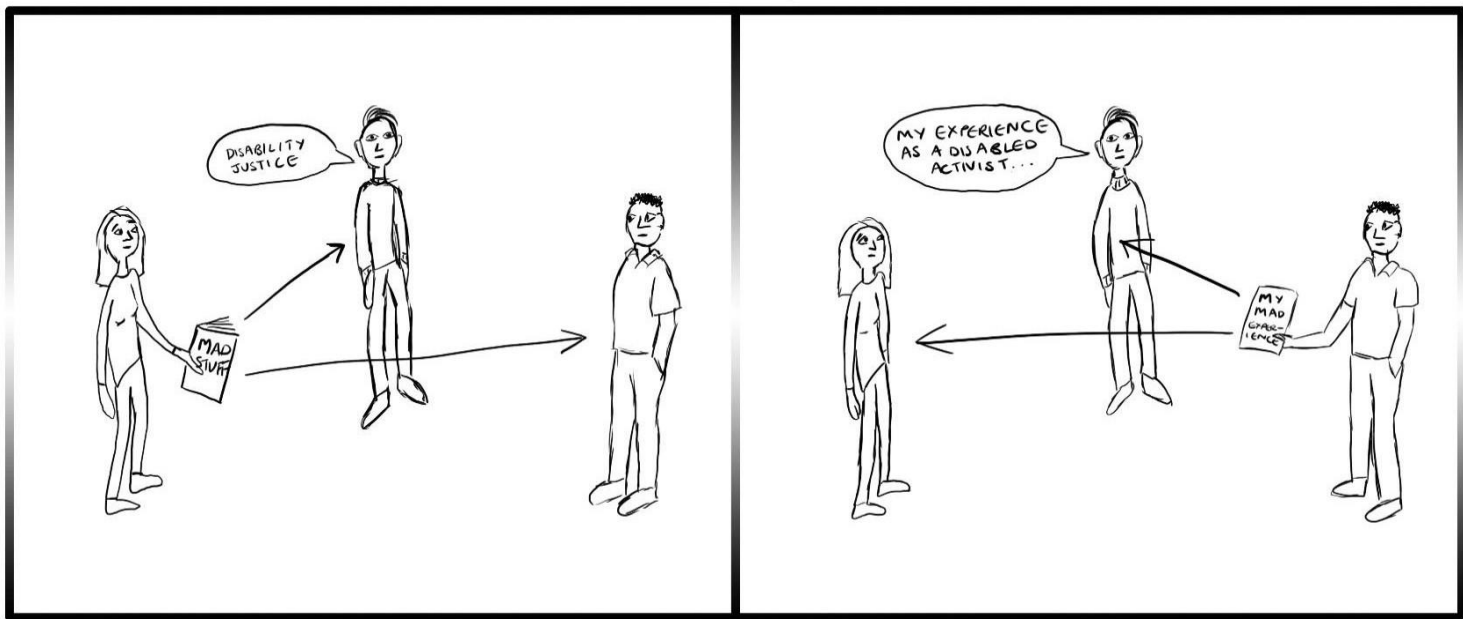


Image 8.7 Identifying shared concerns and building solidarity through sharing zines

Sharing zines within the zine community could be seen as a process of social reflexivity, a form of audience choice that helps inform choice of future actions., LJ suggested that sharing zines can be a way to pool knowledge between people in the zine community, discover commonalities and identify concerns that could be acted upon. LJ gave the example of identifying problematic behaviour through victims sharing their experiences and then individual readers responding to this. LJ described concerns being identified through this process of sharing knowledge. They said:

“It’s often through everyone coming together and being like ‘actually yes, I also had this experience with this person’ or ‘this person is well known to be not a great person’.

Dolly described how sharing her zine enabled her to identify people who shared her concerns. which was a step towards collective action. Dolly said she made and shared her zine about pain *“to start the conversation and know who’s interested in that subject matter, who’s interested taking it further”* and described how she now had other plans for a choir engaging in collective direct action.

Just as a survivor's choice of audience might be in part explained by their aim to engage in a process of social reflexivity, they might choose to create their zines within communities in which people are likely to welcome and understand their testimony for the same reason.

Although most of the survivors spoke about making and sharing zines in isolation, experienced zinesters Luna, LJ, Mary and Lisa spoke about making (some) zines collaboratively. These zines were all made with peers away from the MH system. Luna described making some zines as part of a survivor collective; LJ described facilitating collaborative zine-making with peer support groups and environmental groups; Mary described making zines collaboratively with other survivors; and Lisa described making one of her zines with friends.

Luna's elaboration of the collaborative zine-making process she took part in indicates that it was a process of collaboratively trying to define collective concerns. Luna tic said:

"There's that opportunity during the process of creating something together where we have complex discussions about our experiences and perspectives and stuff. It's collaborative, critical, reflection. Then through that, it's a lot easier to recognize that a lot of our experiences or difficulties that we face aren't personal, but they're systemic. and I think that's a really important part of organizing, as activists."



Image 8.8 Collaborative zine-making as a process of social reflexivity

As Luna notes, engaging in a process of social reflexivity away from the MH system and with other survivors can be a really good way to identify what concerns survivors share and to understand these as systemic rather than individual problems. Survivors engaging in a process of social reflexivity with MH professionals with no experience of madness or using mental health services is unlikely to help survivors achieve this understanding and would not help build or strengthen a sense of shared concern between survivors. For example, if survivors and mental health professionals engaged in dialogue about responses to self-injury in services it may be difficult for the concerns that are common to survivors to be named and reflected upon in order to guide future concerns and actions (similarly the concerns that are common to professionals may not become clear). However, once common concerns have been identified and defined it might then be beneficial for these to be shared.

LJ's process of collaboratively making zines might also be described as a process of social reflexivity. LJ described the zines that they make collaboratively as being a way to bring together "single- or two-page contributions by different members of different communities or groups reflecting on particular experiences." Whilst Mary said of making collaborative zines: "I find that zines are a good way to see if other people are the same as you, or see if other people are

different than you and stuff like that." Creating collaborative zines as LJ describes could be seen as a process of people pooling experiential knowledge, whilst Mary's comment suggests that this process might also be about identifying common concerns.

Mary found making collaborative zines gave her the opportunity to dialogue with people who like her had experienced difficulties with their mental health. This was an opportunity that Mary felt she wouldn't otherwise have. Mary said of making collaborative zines:

"conversations start, and you get to talk to the person about what they wrote and. Um. It's really nice to just like learn from other people and get tips and advice from other people... I don't really know anybody in my life who has had similar experiences to me, so it's not usually people I know in real life. It's usually people like online, in the community, or somebody who's at like a Zine fair or something... I'm sure there are people with mental illness around me, but there's no community where you can reach out to them in person around me that I've found. So, it's nice to be able to have that community somewhere [via zines], even if it's not face to face."

You might say Mary's experience of collaborative zine-making in the zine community enabled her to engage in social reflexivity with other survivors, which she didn't feel she would have the opportunity to do otherwise.

In a similar way to how Dolly described zine sharing within a zine community audience as a step towards collective action, collaborative zine-making could be a step towards survivors having collective influence. Luna said:

"Coming together (to make zines) is really important. It allows us to collaboratively have more influence as a group... [as a] "collective movement for Mad pride or for disability justice."

When individual survivors shared their zines with others, or collaborated with others when making their zines, they were not acting in isolation. Dolly and Luna identified that engaging in this social reflexivity might be a step towards taking collective action.

Some survivors thought identifying shared concerns through making and sharing zines, might be seen as a step towards collective action and influence. For example, Rosie felt zines wouldn't have a large-scale influence or lead directly to social change but that zines:

“can bring people together, or show people that they're not alone. Because if you realise, you're not the only one going through something, then you realize you have allies. So that some people can come together to make changes or to change things in their lives.”

Similarly, Dolly suggested making and sharing zines might involve:

“one person raising awareness of a subject and then having people go “oh yeah that's true, I'll do something about it.” And then it kind of flowers into something more.”

We can relate survivors' zine-making and sharing to what Roy *et al.* (2020) call publics. In their research, Roy *et al.* (2020) used the terms 'first public' to refer to describe the core group of participants and researchers, 'second public' to describe people who were linked to it through an understanding of the context and 'third public' to describe a wider audience who didn't have the opportunity to meet or interact with participants. Essentially, they explore how the less an audience knows about individuals and their context the more risk there might be of individuals experiencing what they call symbolic violence or what Dotson might call epistemic violence. For the novice zinesters, the other participants might be understood as what Roy *et al.* (2020) call a first public because they were all survivors engaged in the same process within the research, whilst the other people they chose to share with might be called a second public in the sense that we all knew the person who made the zine and/or had the opportunity to interact with them. In a similar way, the people experienced survivor zinesters engaged with when making

collaborative zines might be called a first public because they were engaged in the process together, whilst the audience they prioritised sharing finished zines with might be called a second public in the sense that they were people they knew or part of a shared community. In line with what Roy *et al.* (2020) describe survivors not prioritising sharing zines with a wider audience or what Roy *et al.* (2020) might call a third public, is in part a protective strategy. It is a strategy that protects survivors from having their testimony devalued in ways that may or may not be directly harmful and from the associated lack of epistemic confidence. It may also protect them from having their zines misunderstood or even misappropriated.

As already noted in this chapter, through exercising their opportunity to opt into safe(r) dynamics, survivors were able to create and share critical and angry testimony without exposing themselves to the social and personal risks they might experience in the MH system. This included the risk of being pathologised and misinterpreted; the risk of reduced epistemic confidence; the risk of survivors individually or collectively being excluded from sharing any knowledge in the MH system; and the risk of having treatment or support withdrawn or altered. So, making zines in/for the zine community and sharing zines in safe(r) dynamics can be seen as protective strategies. Given the significance of the risks survivors described, it is perhaps unsurprising that some survivors choose to share testimony away from the MH system. Through choosing to create and share zines in power dynamics/relationships where they believed they wouldn't be at risk of harm, survivors might be avoiding what Dotson (2011) has called epistemic violence.

Choosing and prioritising audiences that are expected to understand and welcome testimony and sharing zines in safer dynamics, can be seen as a strategy through which survivors can protect ourselves from harm and from the experience of having our testimony silenced, ignored, misinterpreted or devalued. Through sharing their zines with audiences who they expected to understand and welcome them, survivors avoided not being treated as a knower, which Dotson

(2011) has called testimonial quieting. By choosing an understanding and welcoming audience and opting into a safe(r) dynamic, survivor zinesters can be described as opting into epistemic environments in which they might be seen as capable epistemic agents. This is a strategy which can support epistemic confidence.

Summary

Survivors who were experienced zinesters described there not being deep disadvantageous power imbalances in the zine community and described having freedom and control over the content of their zines. In other words, they didn't have to contend with what Anderson (2012) has called structural testimonial injustice (i.e. the ways in which institutions exclude people from sharing their knowledge). In contrast, survivors who I introduced to zine-making appeared to have been more constrained by the service-based workshops in which they made their zines. That the survivors I introduced to zine-making may not have felt able to exercise the same freedom is significant because it tentatively suggests that the context in which zines are made might affect survivors' sense of agency. Where survivors appear to smother what they reflect on and articulate, this could be described as hermeneutic injustice because it is the process of reflection that is limited not the process of sharing testimony. I will explore the idea that context can be a hermeneutic resource further in the following chapter.

Some experienced survivor zinesters expressed their sense of agency through creating and sharing zines that were angry, critical of and satirised the MH system. Finding ways to resist the MH system may be important for survivors because in the mental system we are perceived to be incapable epistemic contributors and conditioned to rely on conceptual resources and processes created by and for MH professionals. In other words, it is a culture in which our capacity to make sense of our experiences is restricted and where our epistemic confidence is likely to be negatively affected. That survivors were able to create and share zines which are critical of, or satirised, MH services is also significant because criticisms and testimonies seen

as undermining the status of professionals are often not welcome in the MH system. That survivors were able to articulate and share anger is also significant because, as Bailey (2018) has argued, knowledge of injustice (including epistemic injustice) can be entwined with anger. This is especially significant because survivors are particularly vulnerable to having emotions like anger interpreted as psychiatric symptoms.

Survivors indicated that they didn't expect to change the knowledge and understandings (or actions) within the MH system, and they didn't expect their knowledge to be welcomed and valued in the MH system (or other systems they addressed in their zines). In other words, they didn't expect to directly affect systemic change and therefore mostly chose to share their zines with audiences whom they believed would welcome and value them and in dynamics where they didn't feel they had to censor their testimony.

Survivors' choice of audience indicated that it was important to them to be able to share unsmothered testimony. Some survivors clearly described choosing their audience and/or the relationship in which they shared their zines as an intentional strategy. Through exercising their ability to choose their audience and opt into a safe(r) dynamic, survivor zinesters can be described as protecting themselves and opting into epistemic environments in which they might be seen and see themselves as capable epistemic agents. At times, for some survivors sharing or creating zines with peers and/or in the zine community was a process of social reflexivity through which they pooled knowledge and identified (people with whom they) shared concerns. One survivor thought that this process of social reflexivity was an important way to understand that the concerns survivors share are systemic rather than individual. Some saw it as a step towards acting collectively on shared concerns. Sharing angry testimony in a space where it isn't silenced might also be described as a way to step away from the anger-silencing spirals that Bailey (2018) describes.

Culture, identity, valued knowledge and authority

In this chapter I explore the relevance of zine culture. I begin by outlining why survivors opted into zine culture, I then focus on what zine culture offer survivors in terms of recognition of multiple identities, and validation of their positions as knowers. In the third section I relate zine culture to the valuing of specific and contextual knowledge. In the fourth and fifth parts of this chapter I explore how the space of zine culture contrasts with the space of mainstream media and commercialisation, then describe how and why survivors might be perceived as authoritative in zine culture. Finally, I explore how some survivors lack of awareness of zine culture might shape the strategies they use to try and get readers to value their testimony.

In this chapter I primarily focus on what experienced survivor zinesters told me as they were more familiar with, and embedded in, the wider zine community and therefore had ideas of a community in which zines were shared and ideas of what the culture in this community was/is. However, I will also draw on my interviews with the survivors I introduced to zine-making and the zines they made and shared during my research; and my own experience of creating and sharing zines.

When I use the term culture I mean the ideas, beliefs and customs of a group of people or system and when I use the term zine culture I mean the ideas, beliefs and customs in the community in which zines are shared. Specifically, I mean ideas, beliefs and customs that relates to what/which knowledge is valued, who's knowledge is valued and how knowers are evaluated. This will include customs about how identity is conceptualised, ideas, beliefs and expectations about whether knowledge is/must be objective (and generalisable), and customs and expectations about the grounds on which authority is/will be awarded. According to this

definition, reading, making and sharing zines involves participating in (and contributing to) zine culture.

As I outlined in chapter 1, in the MH system there is a culture of seeing/treating knowledge as objective, which disadvantages survivors, and universal, which obscures cultural and other differences. In the MH system survivors are predominantly conceived in terms of mental wellness/illness and people who are perceived to be mentally ill are stereotyped as not being reliable knowers/testifiers. There is also a culture in the MH system of not utilising and valuing concepts and ideas developed by survivors, whereas concepts and ideas developed by and for professionals are utilised and valued.

Zine culture has been described as a culture in which diversity is recognised and valued.

Piepmeyer (2008) writes: "The community of zines does not demand homogeneity or perceived sameness; instead, zine communities are more like what philosopher Iris Marion Young describes as "the ideal of city life," characterized by variety, social differentiation without exclusion, and a heterogeneous public" (p.214-215). In communities in which zines are shared, there is a culture of exchange, and non-commercialisation (Duncombe, 2017; Piepmeyer, 2008, 2009; Richardson, 1996; Liming, 2010; Knobel and Lankshear, 2002; Cameron, 2012; Watson and Bennet, 2021), with zines not being made to gain money or status. There is also a culture of DIY and participation (Duncombe, 2017; Piepmeyer, 2008, 2009; Triggs, 2010), with it being possible for anyone to make and share a zine.

Opting into zine culture

Some experienced survivor zinesters said that by making, sharing and reading zines they were opting into a culture which was created by and for people who were marginalised elsewhere, and which differed from dominant mainstream culture. These survivors were all familiar with what they called the zine community, and often shared their zines via distros, zine fairs, online swapping groups and/or via an online shop which they associated with zines. Dolly described zine culture as made by and for people “*on the outskirts of society*”. Annie spoke about zinesters as being “*political*” and described people making and sharing zines in “*their own community*” in response to being “*systematically silenced*” in other settings. Annie also said zine culture was “*queer*”, as in it challenges traditional approaches (to understanding mental health) and social inequality, unlike mental health campaigns and *raising awareness* which she saw as “*mainstream*” as they represented conventional and dominant ideas of mental health. Luna described making zines as “*actively placing yourself and your work outside of dominant mainstream discourse and aesthetic*”. Rin described zine culture as being about DIY, i.e. it is participatory, and anyone can make and share zines. Luna described making zines as being about creating and sharing “*esoteric knowledge*”, insofar as its not intended for large numbers of people, or people with no prior knowledge, but for other survivors or “*potential allies*”. You could say zinesters chose to opt into zine culture because they saw it as a space in which “*subjugated knowledge*” (Foucault, 1980) would be valued.

Dolly said her zines were mainly about declaring a lack of shame in a context where it was seen as bad to be queer, old, disabled, of colour, and mad. She went on to say that in declaring a lack of shame “*whoever thinks they have that power over me, they don’t have it*” and that Autistic friends had told her “*you take shame out of having a different, unique or diverse mind*”. Annie described being “*a young queer with a history of being in institutions*” as leading to “*stigma and shame*” and, as a result, not being able trust her own voice. In contrast, she described zines having “*a very confident voice*” and linked this to people being able to do things

their own way and not having to “*feel bad for it*”. Similarly, when speaking about making and reading zines by other survivors, Sophie said: “*they’ve helped me to feel more proud and less ashamed*”. Spring (2019) suggests shame is a response to trauma and describes the process of ‘unshaming’ as achieved through therapy. But, shame is also connected to social control and power through the norms that determine what is shameful in a particular society or culture (Dolezal, 2015). Therefore, here I use the term unshaming to refer to a process of avoiding or rejecting the shame associated with cultural norms and social control.

Shame can be described as seeing ourselves negatively because we violate cultural norms, expectations and preferences. If we are a survivor, someone in the mental health system has decided that who we are, or how we experience or behave in the world, in some way violates cultural norms. Survivors accounts of feeling unshamed when making and sharing zines suggests that they do not feel that they violate cultural norms in the zine community. That survivors feel unshamed in the zine community, suggests that it is more culturally acceptable to be mad, traumatised or neuro divergent within the zine community. Mary and Kira notably described creating and sharing zines about their experiences of mental health difficulties despite them both describing these experiences as stigmatised. If something is stigmatised it is essentially marked as shameful, so again sharing stigmatised experiences via zines might be seen as survivors rejecting the shame that we are expected to feel in some spaces. We could see zine culture as contributing towards a process that I call unshaming. This in turn can be good for survivors’ mental health. Dolly says:

“It’s only when I understood, actually I don’t own the shame, it doesn’t belong to me, that my mental health got better.”

This has also been my experience and it’s the reason I titled book about my experiences “Not my shame”.

Dolly also relates shame to different ways she has been oppressed or marginalised, for example she described how when she was growing up, she internalised the racism she experienced and felt shame. She further said:

"It's no accident people in oppressive systems want people to take on that shame and stuff because it's so powerful. So, it [making and sharing her zine] is a tiny little step in saying, "no have your shame back"."

Identity, knowers and epistemic confidence

Some experienced survivor zinesters described being valued and treated as, and treating other survivor zinesters as, what Fricker (2007) calls 'knowers' or 'informants' when sharing and/or reading zines. In terms of being treated as knowers, Lisa and Sophie spoke about people within zine communities learning from their zines. For example, Lisa said of people buying her zines, *"Some people know very little about mental illnesses and they're just intrigued, some people have friends or family who have had mental illnesses and they want to know more about it"* and in relation to her Bulimia zine she said *"I've had people say they are buying it because they want to learn more because a loved one has an eating disorder"*.

Experienced survivor zinesters also spoke about how they treated other zinesters as knowers too. For example, LJ, Dolly and Mary spoke about how they had gained new ways of using language or ways of thinking about mental health experiences from reading other survivors' zines. For example, LJ spoke about learning about the genealogy of the word mad from reading Luna Tic's Mad Activism zine and Dolly spoke about being influenced by a zine about Mad Pride. Mary talked about making zines to share knowledge with others and gaining new understandings through reading zines written by people who *"experienced the same thing as me, but they've come to different conclusions"*. She gave the following example: *"Like, maybe they experienced a panic attack, and, in the end, they realised there was nothing to be scared about rather than I realised, well, that was really scary, I don't want that to happen again"*. Mary

went on to explain how the knowledge she gains from zines has been useful in her life and her zine-making is motivated by wanting to offer a similar experience to others:

“you know if I read a zine and I'm like ‘I've never thought about it that way before’ and it can make a really big difference in my life. And I guess I want to be able to do that for other people too.”

Although Dolly and Annie thought zines might be dismissed by people who don't usually read zines, i.e. people outside the imagined zine community, none of the interviewees described being ignored, unheard, not taken seriously or being regarded as lacking in credibility by people who might usually read zines. You might say that in contrast to the MH system, there is a culture of valuing survivor experiential knowledge testimony in the zine community.

Some experienced survivor zinesters suggested that in the zine community people's knowledge, understanding and interest isn't seen as 'bounded' to single aspects of identity or experience. This extends what was discussed earlier in this thesis, where I outlined the belief in universalism in the MH system (Chapter 1) and how perceptions of (survivors) identities relate to the conceptual and hermeneutic resources relied upon (i.e. perceptions based on concepts of well/ill) in the MH system (chapter 2). Experienced survivor zinesters suggested Identity is conceptualised (and so perceived) in the zine community in ways that contrast with survivors' experiences of the MH system. For example, Rin said *“When you go to a Zine fest. there's a high proportion of queer people, people who are disabled, mentally ill people”* but *“those experiences aren't necessarily centred... It's not like, ‘oh, this is a support group for people who experience that’. It just happens there's a lot of people who've experienced the same things, but it doesn't have to be centred around it”*. Bacevic (2023) used the word bounding to describe where a “speaker's knowledge claim is interpreted by other speakers as constrained ...by the person's perceived identity, social position, personal experience, or combination of these characteristics” (p.1126). Bacevic (2023) described people with marginalised identities as

being constrained through their knowledge being perceived as only relevant to their marginalised identity or experience. An example of this could be where survivors' knowledge is bounded to our survivor identity and experience of being in the MH system and we are perceived as only knowing about the limited personal experience of being an individual survivor in the MH system and not as having wider knowledge about mental health, the MH system or anything else.

This has been my experience in the MH system, but not when making and sharing zines. I think this is because I am seen *only* as a service-user in the MH system but when I make and share zines my identity is recognised as more complex, and my experiences are recognised as more extensive. For example, in the zine community I might be seen as a survivor, an ex mental health worker, a PhD student, a mother and a lesbian and I'm not treated as only able to speak about one of these experiences or from one of these identities.

Similarly, some experienced survivor zinesters expected their identity to be seen as complex in/by the zine community and they articulated and shared knowledge which encompassed their complex identities in their zines. Some of these survivor zinesters said they hadn't seen these complex and multiply marginalised identities recognised or represented in other places or mediums. Experienced survivor zinesters LJ, Dolly, Lisa, Kirsty and Rin didn't feel they had to write about only one aspect of their identity and experience when making and sharing zines. For example, LJ described writing zines about being queer *and* neurodivergent *and* going cycling because they didn't see these things brought together in mainstream literature. In addition, Dolly described writing a zine about being disabled *and* a lesbian because this experience was missing from the medical literature she was given and Lisa wrote a zine about being depressed *and* gardening because she felt that whilst in mainstream culture a gardener is only a gardener, in the zine community it might be recognised that someone could be a gardener *and* be depressed.

Similarly, Rin spoke about creating a zine series called “that’s how it feels for me” which was about having been diagnosed with autism later in life and being queer and being non monogamous; Kirsty describes her perzine series *Forever Incomplete* as being about “*mental health*” and “gay stuff” and “fandom” and “trying to be an adult”; and I have written zines about being a survivor and a mum and a lesbian. In terms of reading zines, Sophie said of one of her favourite zines was *Doll Hospital* by Bethany Rose Lamont precisely because it discusses multiple aspects of people’s experiences:

“The zine is all about mental health, intersectional feminism, transphobia, racism, homophobia. So, it doesn’t just talk about mental health in isolation. It talks about it along with other things and other injustices that people are facing.”

In relation to mental health services, Annie described how she was only perceived in terms of her mental health, whilst in addictions services she was only perceived in terms of her addiction. Annie described creating her Good Patient zine about mental health and addiction and contrasted being able to do this with her experiences of services in which things were understood in terms of mental health OR addiction. She suggested that, because experience was only understood in terms of mental health in the MH system and only understood in terms of addiction in addiction services, there is a lack of understanding of how they crossover in people’s lives:

“When you see people trying to stop pill shaming and being like ‘its ok to take meds’, no one really mentions taking meds for addiction. It’s interesting because it really overlaps. I think it’s down to the way services are designed, they’re really separate, and I think that reflects the way people approach addiction. ...We have really strict notions but sometimes they overlap, especially with BPD or trauma, you know addiction is going to be part of the package for a lot of people.”

As in Annie's example, when survivors make and share zines, knowledge can be centred around understanding an individual's experience instead of being organised around, and compartmentalised within, diagnostic categories. This is again about how survivors are conceptualised in the zine community vs the MH system; how we can be seen as having multiple overlapping experiences in zine culture but, in the MH system, our experiences tend to be conceptualised and treated as separate.

Recognition that identities are/can be complex can mean that intersectional experiences can be shared within the zine community. In an interview with Time magazine in 2020, Crenshaw described intersectionality as “a prism, for seeing the way in which various forms of inequality often operate together and exacerbate each other” (Steinmetz 2020). Dolly linked seeing identity as complex in the zine community with zines being a good tool for raising awareness about “things around intersectionality”. Dolly said through her zines she can be visible in the zine community as a person who is mad, fat, has lived as a woman for nearly 50 years, has physical disabilities, is a person of colour, queer and working class. She linked this with being able to raise awareness of how experiences of inequality intersect, for example by making a zine about her experiences of “*ableism in the queer community*”. In a similar way, I have made zines in which I've written about being a lesbian survivor and described how my experiences of homophobia, misogyny and sanism intersect, which is not something I have been able to speak about or heard others speak about within the MH system, although these are things survivors have written about in other settings e.g. Dolly has recently edited three books written by survivors about this (Sen 2023, 2024, 2024a).

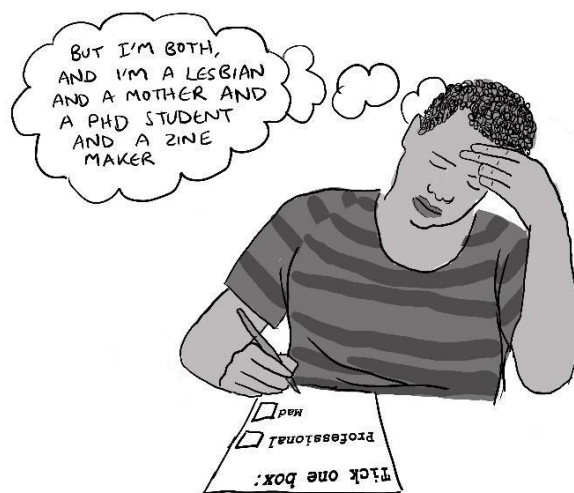


Image 9.1 Identity is not singular

Being able to express the ways in which our experiences and identities overlap is important for us to be able to share knowledge of intersectional experiences. It is also important because how identity is conceptualised is linked to how survivors can be perceived. If survivors are conceptualised as *only* mental health system users/mentally ill, we will be perceived only through this lens, and where this is associated with stereotypes about not being a capable knower then this makes it extremely difficult for us to be seen to be anything other than people whose knowledge is ‘bounded’ and/or untrustworthy.

Experienced survivor zinesters Dolly, Sophie, Rin, LJ and Kirsty all said the culture in the zine community was one in which they were not seen exclusively, or even primarily, in terms of their survivor identity or mental health status. Sophie and Dolly linked this to been seen, and seeing themselves, in terms of their capabilities and strengths as well as their survivor identity. For example, Dolly said that when survivors make and distribute zines “*you’re not just a mad person you’re also a writer and an artist as well*” whilst Sophie said, “*Zines have made me feel like you can be two things at once*”. Sophie described how making zines enabled her to realise she “*can do things, and really its other people’s limitations of you, it’s not an actual limitation.*” Like Dolly and Sophie, I have found that because the focus of zine culture is zines and not mental health,

my mental health status is not seen as defining my identity and I can be seen (and see myself) as a zinester instead of, or in addition to, being a survivor.

Like Sophie, being seen as a zinester enables me to be seen and see myself in terms of my capabilities and strengths, in addition to, or instead of the negative assumptions and perceptions that are linked to being a user of mental health services. It increases my epistemic confidence because I sense that my knowledge is more likely to be trusted and valued. It is not possible to claim that the prejudicial stereotypes of survivors that disadvantage us in the MH system do not exist in zine culture. However, because our survivor identity is not the only lens through which we are seen in the zine community, sharing zines in this context seems likely positively benefit our individual and collective epistemic confidence. The image below depicts how I imagine the Mad aspect of a survivor zinester's identity might pull against the weight given to other aspects of the zinester's identity when the reliability of a zinester's testimony is being assessed.

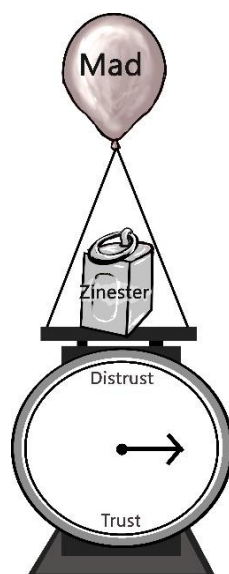


Image 9.2 Balancing survivor identity and zinester identity when evaluating survivor zinesters' testimony

Annie, Mary, Rin and Kirsty all linked the culture of the zine community with seeing themselves as valid knowledge contributors. For example, Rin linked making zines to recognising that their

contribution has value (whether it is different from that of other contributors or not), whilst Kirsty linked reading and making zines to “feel(ing) like what you have to say is useful, or valuable, or at least no less boring than what any other fucker has to say”. Like Annie, Mary, Rin and Kirsty I have found that I am seen and can begin to see myself, as a capable epistemic agent in the zine community. Indeed, I’ve realised that I am only able to see myself as someone who might be a capable epistemic agent when I have access to environments like the zine community in which I am seen as a knower.

Annie and Mary suggested that people might need to boost their epistemic confidence after being silenced and/or treated as not being trusted and valued knowers. Mary said if people are used to feeling shut down and silenced then it makes sense they would want to make use of a space *“that would allow us to be heard and feel like we’re important”*. Mary also said, *“I think that’s really important to healing with mental health, feeling what you’re saying and what you’re thinking is important in some way, that it’s OK to have ideas and your own thoughts.”* Annie said that after being silenced in services it became very hard for her to trust her own voice but that sharing her zines was about *“trusting that your voice is valid”*.

Like Annie, I feel that my experiences of not being treated as a capable epistemic agent in the MH system seriously damaged my epistemic confidence and this is partly why I need access to spaces where I am seen and can see myself as, a capable epistemic agent. After over ten years in services, much of which were during my formative years, I still struggle to trust my ability to know my experiences, even outside of the MH system, especially where they conflict with, or don’t conform to, dominant narratives or interpretations. You could say I became habituated to an environment in which I was seen as an epistemic object, but that by opting into zine culture I am trying to habituate myself to the idea that survivors are/can/will be valued as epistemic agents. My belief that as a survivor I cannot be trusted to know, and cannot trust myself to know, led to me silence myself and this sometimes made thinking itself difficult. However, the

more time I spend in spaces like the zine community, where I am treated as a capable epistemic agent, the more confident I become about my epistemic ability, the less I silence myself and the easier it is to think.

Valuing specific contextual knowledge

LJ described zine culture as being a culture of “valuing different types of knowledges and ways of knowing and ways of talking and speaking” and other experienced survivor zinesters spoke about there being a recognition in the zine community that knowledge is subjective and should be valued. For example, Sophie spoke about sharing information about her life but ‘not in a factual way” and Mary said she was “trying to give the insight as a patient rather than as a doctor”. This contrasts with the MH system where it has been argued that there is a belief in the objectivity of MH knowledge, which disadvantages survivors.

Similarly, some experienced survivor zinesters described zine culture as valuing specific and contextual knowledge and spoke about not generalising from specific experiences but sharing and learning from specific experiences. For example, LJ spoke about how instead of trying or claiming to create “*generalizable rules about cycle touring*” they co-wrote a zine about what they learned and found useful when they went on their cycle tour as “*two neuro divergent, queer people*”. Similarly, Lisa contrasted their zine about depressed houseplant owners with generic guides which assume everyone “*will be able to mist a fern twice a day every day*”. In addition, Luna spoke about contextualising knowledge in her zines through making links between personal, historical and political perspectives, whilst Kirsty described zines as being about “a way that it is possible for a human to be” and linked this to there not being an expectation in zine culture that people adopt/use a pre-made story/template.

Not treating knowledge as generic is linked to the representation of intersectional experiences and complex identities in zines. Notably experienced survivor zinesters weren’t generalising from specific accounts because they don’t believe that knowledge is or should be universal or

even widely applicable. Kirsty described zine culture as including a diversity of stories where you might not find someone who is the same as you, but you will learn about lots of different ways of being in and making sense of the world. In other words, you might not (expect to) find generic widely applicable knowledge, but you can gain knowledge about lots of very different specific experiences. In contrast, within the MH system, knowledge tends to be perceived as universal and generalisable, and this can obscure survivors' specific experiences e.g. what is thought to be generally true for survivors will be assumed to be true for all survivors or what is thought to be true for people with a particular diagnosis will be assumed to be true for everyone who is given that diagnosis. You could argue that the zine community recognises and values multiple subjective perspectives and experiences.

Anti commercialisation

Some experienced survivor zinesters suggested that the specific subjective and intersectional knowledge shared via zines cannot be, or at least is not, shared in the mainstream media. For example, Lisa spoke about how mainstream media would produce generic information about looking after a houseplant instead of a houseplant guide for people who were depressed and said that, because zine makers weren't trying to make money, "there's very little pressure to cultivate what you are doing to an audience". Kirsty went further, suggesting that it is possible to share knowledge about complex identities and experiences in the zine community because zines aren't intended to be commercial. She suggested that, in order to appeal to a wider mainstream audience and be commercially viable, people would have to share simplified, stereotypical generic accounts of identities. Kirsty said: *"If you pick up a copy of Cosmopolitan...that's a version of someone ... but it's not personal"*, whereas when you read zines *"its unfiltered, it's not about 'what is this kind of person supposed to be', it's like 'who is this individual?'"*.

Although some people in the zine community do make zines to sell, for the zinesters I spoke to making and sharing zines wasn't about making money. Lisa described zine culture as "anti-

capitalist” and she and LJ both spoke about the ethos of zine culture being about not making money out of zines. Lisa related this to “perzines and DIY type zines” specifically and LJ spoke about having “DIY-y” ethos and values. Dolly said that whilst some people want to make money out of zines this wasn’t her motivation, whilst Mary and Luna spoke about providing some of their zines for free. Like LJ, Lisa, Dolly and Mary I don’t make and share zines to make money and, as Kirsty suggests, I think this frees me from trying to create more generic understandings or widely relatable accounts.

The image below depicts how the way in which identity is conceptualised is one facet of how authority might be evaluated and awarded.

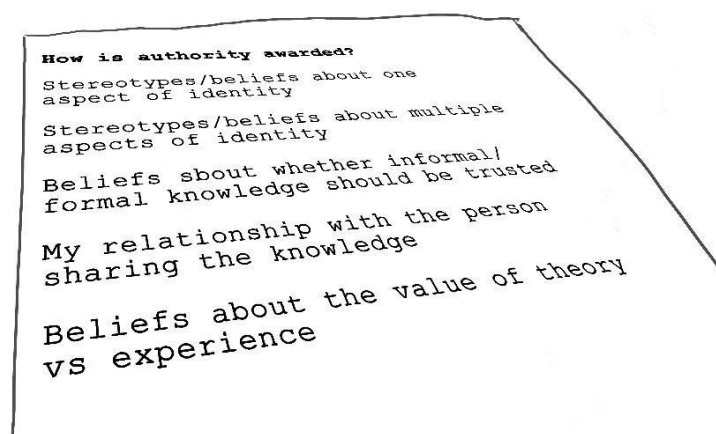


Image 9.4 culture and authority

Relational and vernacular authority

The authority some experienced survivor zinesters described as valued in zine culture might be called relational authority. This has been referred to as “the credibility of those individuals and resources whose accountability lies not with a remote institutional affiliation, but exists within the community” (Brady, 2001, p.7). Experienced survivor zinester LJ addressed this explicitly. They suggested zine readers also trust and act on the knowledge in zines because there is a sense of personal connection. The sense of personal connection was linked to zine readers seeing zinesters as being part of the same community:

“You can make them anonymously, but because you're distributing them still within your community, they carry weight and authenticity that don't require your name to be attached to them.”

LJ emphasised that when sharing information within the zine community they felt they were able to act on the trust engendered by the sense of personal connection without having to know the name of an individual. In addition, here was a sense of trust and personal connection which was based on being part of the zine community and having an idea of the people who would be in that community:

“You know, a zine is anonymous, it doesn't have a name on it, but you also know that the person who, you know the person who made it in a way. You're just like, OK, I know you because you're a member of this community. I know you're part of this so like you don't have to name yourself or be identifiable for me to give weight to what you're saying, to understand the knowledge that you're sharing and to think about the implications of that for my own life, or like join up those dots or take this action”

LJ suggested that the sense of personal connection and trust in the zine community is related to zines' material quality and the ways in which they are shared. Essentially, because zines are physical, handmade documents they bring to readers' minds the individual who has made them and because readers can have direct interactions with zinesters this can add to the sense of personal connection and trust. This sense of personal connection engenders authority because it creates a sense of intimacy and accountability:

“Having something that's like much more like tangible and personal and like solid I think is like quite effective at like bringing something to people's attention and also giving them a sense of like, it's actual like consequences or impact, or like a personal connection. 'Cause I think like zines often, like for me anyway, are like an embodiment of, or a materialization of, like a personal connection. They're like an extension of me, or

like what I put in zines is an extension of me. So, like that person gets to speak, or they get to interact with me through them. And also, not just me through them, like metaphorically but actually me through them if they want to. You know, like there's the actual way of them reaching the person that produced the zine and having that conversation, or like feeling that connection."

Luna, Annie, LJ, Rin and Sophie all linked making their zines by hand to creating personal connections with readers. Luna, Annie and LJ said that, for them, the process of making things by hand was about wanting to connect with readers, Rin described embroidering zines they had made to encourage people who were struggling, and Sophie said that she sees digital media as useful for political organising or getting a message to large numbers of people whilst zines are "good for friendship or comfort". Annie spoke about creating handmade elements which were tailored to individual readers, and said making them by hand is "connected to that feeling of wanting to connect to someone" and said that when she made things by hand for readers of one of her zines it felt like "sending care". Luna said: "The hand making them in the handwriting them is a kind of deliberate act to try and connect with people." Luna also spoke about touch via zines: "I think especially during Corona, there's something really special about touching something that I know something else, someone else, has touched."

LJ described zines as "an embodiment of, or a materialization of, like a personal connection". When speaking about sharing zines within a person's own community, LJ also suggested "Having something that's like much more tangible, personal and solid I think is quite effective at like bringing something to people's attention and also giving them a sense of it's actual like consequences or impact, or like a personal connection." LJ pointed out that with digital media, readers might not even know if the content has been produced by a human being, they said "if you make a burner social media account you could just be a Russian bot, but as far as I know, Russian bots don't yet make zines."

It is worth noting that survivors who were new to zine-making expressed some concerns that handmade zines would not be valued by readers. Bex, Nazrah, Diane and Kaz all said that they didn't think handmade mediums would be valued outside of their personal contacts and certainly not in/by services. This chimes with my own beliefs before I was familiar with zine communities. Indeed, it is only as I have become more familiar with the culture in zine communities that I have come to recognise that there are spaces where documents may be valued precisely because they are made by hand. Prior to this, my experience had been that more professional documents seemed to be more likely to be taken on board and that being 'professional' meant stripping away individuality and intimacy and therefore definitely did not include handmade objects like zines. Yet, despite their concerns Bex, Nazrah, Diane and Kaz did all share their zines and didn't indicate that they felt readers had devalued their zines because they were handmade. This may be because they shared their zines with people they had a personal relationship with and, in Bex's case, with an arts organisation, not with service providers.

Experienced zinesters Lisa, Annie, Luna and LJ all described informal knowledge and ways of knowing as being valued in the zine community. Lisa and Annie spoke about not seeking institutional validation in zine culture and Lisa linked this to her gaining confidence. LJ described the point of zines as being about a "different way of knowing about things that isn't necessarily about academic or formal knowledge" and although Rin noted that in some parts of the zine community the culture was more professional and less DIY, this didn't apply to the part they were involved in. In other words, organisations didn't gate-keep what knowledge is shared or valued, or how. This is important because gate-keeping knowledge is often how institutions maintain unequal power dynamics in wider cultures. The image below represents the process of institutions formally recognising the value of knowledge, e.g. through awarding qualifications, job titles, and pay.



Image 9.5 Institutional recognition

Experienced zinesters Annie and Luna said one of the reasons they chose to make zines was because there wasn't an expectation that knowledge should be formally or institutionally recognised, to be valued in the zine community. Annie said that in order to stop seeking institutionalised recognition she had to change her ideas about success and Kirsty expressed suspicions about the motives of mass produced, institutionally funded testimony:

"Once you go beyond... 1000 issues who's paying for it, what's the motivation behind that budget? It becomes quite different from someone saying, 'this is something that's really important to me and I'm going to photocopy it and I'm going to put copies of it in library books'".

For some survivors, not being commercially motivated or institutionally recognised seemed to be what made zines trustworthy. You could also describe the zine community as valuing 'vernacular knowledge' (Valk *et al.*, 2022) rather than institutional knowledge. Vernacular knowledge is knowledge that challenges institutional and official knowledge (Valk *et al.*, 2022). You could also say the zine community values *vernacular authority*. Vernacular authority refers to authority which "emerges when an individual makes appeals that rely on trust specifically because they are not institutional" (Howard, 2013, p.81). This image below represents how I see survivors accounts of authority and identity in zine culture.



Image 9.6 Relational and vernacular authority

Experienced zinesters described informal survivor-created language and concepts being shared and valued in the zine community. For example, Luna spoke about not having to use academic or clinical language in zines and told me that she drew on the work of other survivor activists when making her zines. As described earlier, Annie spoke about being able to make her zines because she had benefited from mad activism and could build on this in her zines and LJ described getting the word ‘mad’ from zines and being able to use it in their zines. They said: “I came across zines, and I learned that I can just say that I went mad and that that's an acceptable way of describing [it]... and of all the ways I've been offered to talk about what happens, that felt the one most honest and like useful”. LJ contrasted this experience of the zine community with their experience of the MH system where they described being expected to frame their experiences as illness and make use of conceptual resources made by and for MH professionals.

None of the survivors I spoke to described needing to rely on conceptual resources and language created by and for MH professionals in the zine community. Luna, Annie and LJ all spoke about being able to use informal language or conceptual resources and language created by and for survivors.

Experienced survivor zinesters appear to be able to articulate and share knowledge grounded in their lived experiences and survivor perspectives and expect this to be valued in the zine community. All the survivor zinesters I spoke to said they included lived experience and first-person perspectives in their zines. LJ said, “the point of zines is about the importance of the personal and the linking of things to your life” and Lisa said people in the zine community told her that they had bought her zine, which is a first-person account, because they want to learn from it. Lisa also said that she had learnt through reading people’s accounts of their lived experience in their zines. You might say that in zine culture there was a valuing of what Brady (2001, p.7) calls “experiential authority”. This, in turn, may help the development of concepts grounded in survivors’ lived experiences.

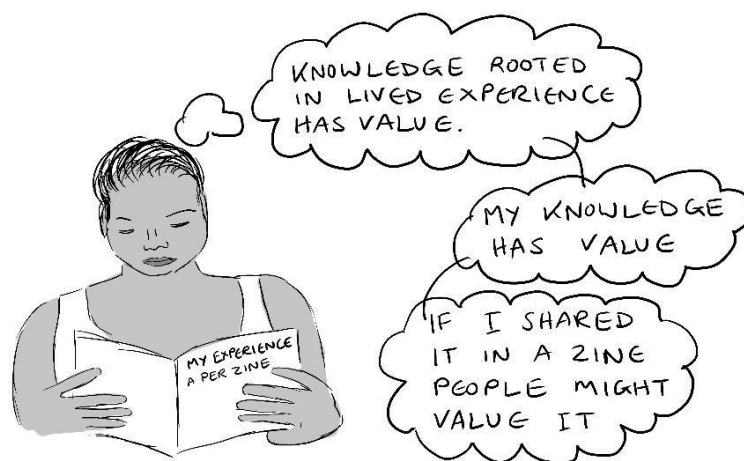


Image 9.7 Experiential authority and subjective knowledge

Awareness of zine culture

Some survivors who were new to zine-making seemed to make use of relational authority (and possibly experiential authority) but not vernacular authority. This was the case where survivors were completely unfamiliar with zines, zine-making and people who might read zines. Out of the survivors who were new to making zines, four had never heard of zines before and hadn’t read zines or heard of zine fairs or distros. In other words, four were unfamiliar with the idea of a zine community and culture. Two of these zinesters, Diane and Kaz, tried to draw on

institutional authority in their zines, whilst the zinester I had introduced to zine-making who was most familiar with zines, the zine community and zine culture (Bex) very definitely prioritised vernacular knowledge over institutional knowledge in her zines.

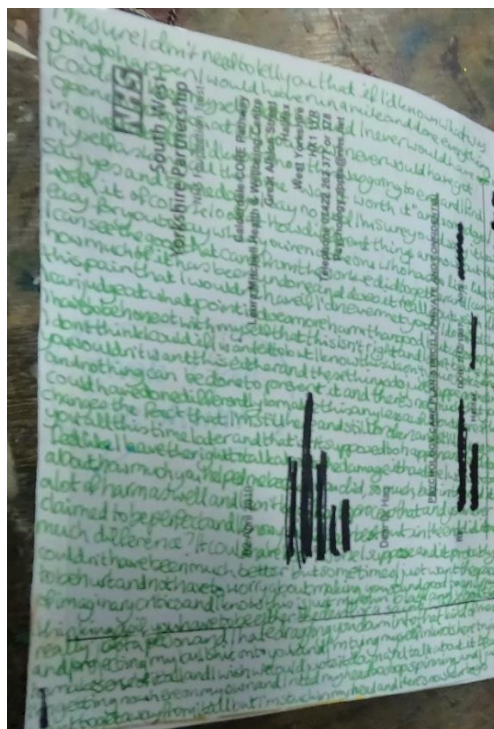


Image 9.8 Page from Bex's zine

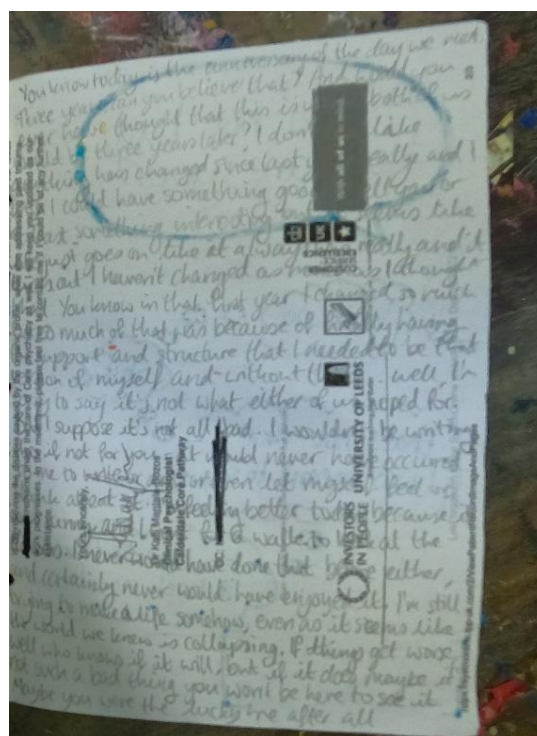


Image 9.9 Page from Bex's zine

Bex contrasted formal narratives with her personal understandings in her zines and when she did so, she foregrounded the personal. For example, Bex handwrote about her personal understandings and experiences over the top of clinical letters written about her (see image 9.8 and 9.9 for examples). By foregrounding personal writing over a clinical letter, Bex indicates that the reader is expected to prioritise the personal text over the formal text, demonstrates her valuing of personal and informal knowledge and calls for the reader to do the same. In doing this, Bex is both drawing on a culture in which personal and informal knowledge is valued and she is helping to develop a culture in which personal and informal knowledge is valued.

children that grow up in local authority care are more likely to end up in jail as an adult. We need to take better care and education to these young ones often lost in a system. For a lifetime. Open doors and opportunities given to others.

However looked after children achieve slightly better in school than children in a abusive unhappy household. Its better to be in care than in a turbulent home. My experience was a childrens home was that it saved me from abuse. I felt free.

The number of children in care in the UK are increasing overall. Foster care is the most common placement type. We also need more great foster carers!

Image 9.10 Page from Diane's zine

Image 9.11 Page from Diane's zine

Image 9.12 Page from Diane's zine

Psalm 82:3
"Defend the cause of the weak and fatherless; maintain the rights of the poor and oppressed."
Bible

Abandoned children should still be valued they are precious souls.
Sister  Brother
Someones daughter
Someones son 
child of most high

Image 9.13 Front cover of Diane's zine

Image 9.14 Page from Diane's zine

In contrast, Diane drew on external authority in her zine and did not draw on experiential and vernacular authority which seems to be more common in zine communities. For example, Diane drew on official statistics and knowledge, as well as experiential knowledge, to create the text on pages 3 and 5 of her zine (image 9.10 and image 9.12). When she was making her zine, Diane asked me to provide official statistics and information that she could use in her zine. When I asked her about this, she said that she wanted this because in the past she had found that she could get people to believe her if she could provide official statistics that backed up her experiential knowledge. It transpired that when Diane shared formal knowledge and statistics about institutional racism she had been believed and valued, whereas when she had drawn on

her personal knowledge and experiences this had been disbelieved. As well as drawing on official statistics, Diane used quotes from the bible and drew on the authority of God to back up what she was saying in her zine (image 9.13 and image 9.14). Diane said she knew knowledge based on lived experience was important but, in her experience, people didn't value this.



Image 9.14 Drawing on external authority

Similarly, when I first started making zines, I often included quotes or references to research because, like Diane and Kaz, I found it difficult to imagine a culture in which I didn't have to draw on institutionally recognised knowledge, theories and language. It has only been through reading more zines, attending zine fairs and speaking with people who make and read zines that I have become acclimatised to the idea that non-institutional (vernacular) knowledge is more likely to be awarded authority in the zine community.

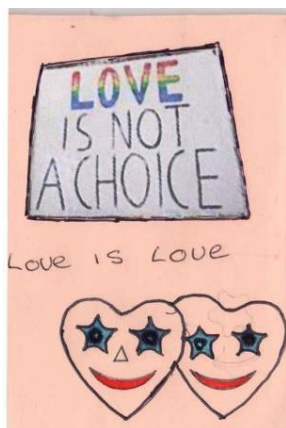


Image 9.15 Page from Kaz's zine

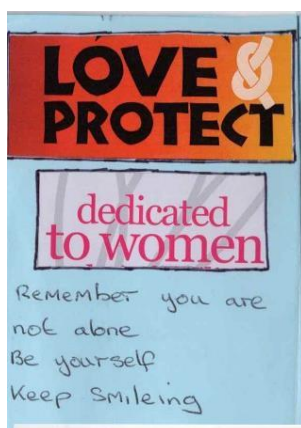
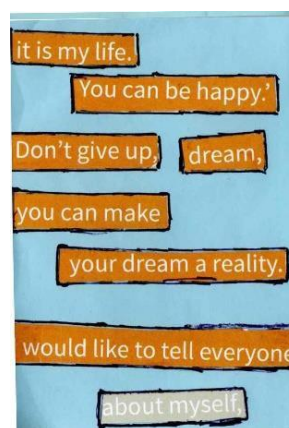


Image 9.16 Page from Kaz's zine



Page from Kaz's zine

When making her zine, Kaz said that she researched homophobia online because she wanted to include official facts to back up her experience of homophobia. Kaz made use of images and text found on institutional websites in her zine and included text from leaflets about the service she was accessing. In other words, Kaz drew on the institutional authority of text and images to back up what she wrote and drew about her own experience.

If people don't have access to a community in which experiential knowledge and individual authority is valued, then it makes sense that they would draw on external authority in an attempt for their experiential knowledge to be heard and valued. However, in order to be able to draw on a culture of using experiential and vernacular authority we need to be familiar with this culture. During the zine-making workshops I said that I valued experiential knowledge, but I didn't speak about the culture of valuing experiential knowledge in the zine community. Even if I had, being told about a culture and experiencing it are not synonymous and it takes time to acclimatise to the values of unfamiliar cultures.

Summary

Not being perceived only in terms of one's mental health status in the zine community can help survivors feel seen, and see ourselves, as valid knowers. Experienced zinesters described a culture of valuing survivors as knowers, and recognising complex identities, within the zine community. Being perceived as a zinester as well as a survivor meant that survivors could be

seen in terms of their strengths, and recognition of complex identities meant that survivors' knowledge was not seen as bounded to a single aspect of their identity or experience.

Survivors are seen in the MH system as violating social norms and are expected to take on this view of themselves. We are not required to do this in the zine culture, which is partly why survivors opt into this. Experienced survivor zinesters' accounts of sharing zines as being a process of what might be referred to as unshaming suggest that it is culturally acceptable to be mad within the zine community. It also suggests that shame might play a role in silencing survivors accounts in other contexts, especially MH in services

There is a culture in the zine community of creating, sharing, reading and valuing accounts of complex intersectional experiences whereas these experiences are not often shared and recognised in the MH system. These experiences may be shared and valued in the zine community because there is a recognition in the zine community that identities are complex and because knowledge isn't expected to be universal or even widely applicable. Whilst in the MH system there is a culture of perceiving (dominant/institutionally valued/professional) knowledge as objective, in the zine community there is a culture of perceiving all knowledge as subjective and recognising and valuing multiple perspectives, understandings and experiences. In other words, in zine culture, one way of understanding and perceiving isn't valued above all others. Not trying to create commercially viable documents can also help enable survivors to articulate and share zines about specific, complex and intersectional experiences.

Survivor zinesters who were habituated to a culture in which their voices were not seen as valid particularly valued being able to access an environment in which they could be recognised and valued as knowers. Being recognised and valued as a knower can combat shame and can benefit survivors' epistemic confidence. If epistemic confidence is important to articulating knowledge, then epistemic confidence or environments which support it might be described as hermeneutic resources. Fricker (2007) writes about loss of epistemic confidence only as a harm

resulting from epistemic injustice. However, if loss of epistemic confidence is part of a pattern of silencing, then Dotson (2014) might describe it as epistemic oppression and, if the silencing also causes harm, Dotson might describe it as epistemic violence (2011). Therefore, zine culture might be seen as helping survivors address epistemic oppression and violence through supporting survivors to gain epistemic confidence.

Experienced survivor zinesters described people being valued as knowers in the zine community because they had what Brady (2001) calls relational authority through personal connection. The personal connection was, in turn, linked to the material and handmade qualities of zines and the ways in which they are (directly) shared, this echoes what other zine scholars have written about zines and personal connection (Triggs, 2010; Cameron, 2012; Piepmeier, 2009; Watson and Bennet, 2021). These qualities were valued in personal relationships, and the zine community, but not in formal settings.

Experienced survivor zinesters described lived experience and informal knowledge and ways of knowing as being valued in zine culture. Indeed, trusting and valuing vernacular authority was why some survivors made and shared zines as they saw it as a way to avoid seeking/requiring institutional recognition. The culture of valuing of vernacular knowledge may be linked to the lack of institutionalisation of value within the zine community.

When I introduced survivors to zine-making some of them used formal/institutional knowledge to try and gain authority, especially if they weren't aware zines or wider zine cultures. This may have been because, when making their zines, they weren't sure who their readers might be and/or it might have been because they were unfamiliar with the valuing of vernacular authority in the zine community. It might also be because I hadn't sufficiently communicated the existence of this culture and/or I wasn't able to recreate this culture in the workshop settings.

In the MH system people are seen only in terms of service-user identity /mental health status and these identities are often linked with negative stereotypes. Whereas in zine culture identity

is seen as complex and multiple. This means that survivors are not seen as a homogenous group, and what we are perceived as knowing isn't dependent on our survivor identity and mental health status. Survivors' knowledge is not bounded to our survivor identity in zine culture, and we can share intersectional experiences and complex nuanced accounts in the zine community that are missing from the MH system.

In the next chapter I explore to what effect survivors use zines and zine-making to reflect on and articulate their experiences and how, why and to what effect survivors share their knowledge, understandings and experiences via zines. In particular, I discuss how the theories of epistemic injustice I have introduced might help us understand how survivors might use zines to work towards epistemic justice. I discuss what my findings suggest about the theories and reflect on what other theories might add.

Epistemic in/justice and agency.

This chapter draws together my findings with theories of epistemic injustice and Archer's (2000) ideas about agency, to discuss what is offered by the theories introduced in Chapter 2, and additional concepts that I found useful for understanding my findings. I first briefly recap some of the opportunities making and sharing zines afforded survivors and the strategies they employed when doing this. I then explore how theories of epistemic injustice outlined in chapter 2 can help conceptualise survivors' use of zines, and demonstrate how I have used them to extend my analysis. Finally, I introduce additional theories and images that help further understand survivors' strategies for epistemic justice. Like the survivors in my study, I don't see theory/concepts as the only way to understand experience, so I reflect on the limitations of using theory to help make sense of my findings and I conclude with a picture.

Opportunities and strategies

Survivors described making and sharing zines as affording them a range of different opportunities and engaging in a variety of strategies when creating and sharing their zines. These opportunities enabled individual reflection, articulation and communication. The strategies related to: protecting survivors; engaging in shared sensemaking, social reflexivity and/or alliance building; and accessing or developing resources which might support reflective processes.

Enabling individual reflection, articulation and communication

Survivors variously found helpful: the handmade nature of zine-making; the flexibility of the structure; the creative, visual and sculptural qualities of zines; their enjoyment of the zine-making process; and the sense of containment or distance zines could provide. These elements supported survivors to reflect on, articulate, share and communicate: contextual and comparative links; emotional experiences; experiences of dissociation and madness; and

experiences they hadn't made sense of. They also supported survivors to reflect on, articulate, share and communicate experiences of MH services. Some survivors also felt that visual processes or non-linear articulation suited or represented the way that they think.

Additionally, survivors valued: the sense of freedom and control associated with creating zines away from the mental health system; the ability to imagine and share zines with receptive audiences; and the associated sense of safety. These enabled some survivors to reflect on, articulate and share zines in which they expressed anger at and criticisms of MH services and professionals.

Protective strategies

Survivors employed a variety of strategies which can be described as protective, in the sense of protective from dismissiveness, shame, and negative responses. For example: some survivors used zines as creative objects to create distance between themselves and the contents of their zines as a way to reduce the risk associated with sharing zines on topics they felt were taboo; one survivor used confusing structures and sculptural qualities to try and test readers commitment; and I share zines in which interpretive links are not explicit as a way to protect myself from negative responses to my interpretations. Additionally, some survivors created and shared their zines away from MH services, in the zine community and/or with other welcoming communities, as a way to protect themselves from having their testimony devalued, some did this as a way to avoid the risks associated with sharing (critical and angry) testimony in the MH system, some used it as a way to avoid or reduce shame, and one survivor saw this as a way to resist internalising the culture and perspectives of the MH system. Some survivors linked their use of protective strategies to their experiences of, or expectations of, harm in relation to sharing testimony in mental health services.

Shared sensemaking, social reflexivity and alliance building

Using a non-linear structure was seen as a means of shared sensemaking by one survivor as it can invite readers into the sensemaking process, and some survivors created and shared their zines in the zine community and/or with other welcoming communities as a way to pool knowledge and/or engage in a process of social reflexivity. One survivor thought that making zines in this context might enable them to identify what concerns survivors share and understand these as systemic rather than individual. Additionally, one survivor described sharing zines in this context as a way to turn potential allies into actual allies and another described it as a step towards collective action.

Accessing or developing resources

Some survivors created and shared their zines away from MH services, in the zine community and/or with other welcoming communities as a way to support their epistemic confidence. Engaging with the zine community was also described as a way in which survivors could access survivor created concepts and language which could then be used to reflect on and articulate experience.

Theories as tools for understanding survivors use of zines

Here I relate my findings about survivors' use of zines, to theories of epistemic injustice and Archer's (2000) theory of agency. I reflect on how these theories can help us to understand constraints on survivors' epistemic capacities and how survivors might use zines to work towards epistemic justice. I also identify where theories might limit this understanding and suggest ways in which they might developed further. I begin by outlining my findings in relation to some key ideas and particular concepts outlined in chapter 2 that I've found useful to understand my findings. I then introduce other theories which I've found helpful.

In this order, I reflect on the following key concepts: hermeneutic injustice and testimonial injustice (Fricker, 2007, 2013); testimonial quieting, epistemic oppression and violence (Dotson

2011); structural testimonial injustice (Anderson, 2012); tone management/policing (Bailey, 2018); concept of testimonial smothering (Dotson, 2011); schemata, practice and epistemic systems (Dotson, 2014) contributory injustice (Dotson, 2012) and wilful ignorance (Pohlhaus, 2011).

Hermeneutic in/justice

Fricker's (2007) account of hermeneutic injustice describes how people need hermeneutic resources with which they can interpret their experiences. This was a useful idea for thinking about the ways in which survivors used their zine-making to reflect on and articulate experience. However, survivors' reflection and articulation was enabled by a wide range of zine qualities, zine-making qualities and contextual qualities, whereas Fricker's (2007) account implies that hermeneutic resources are primarily conceptual. Therefore, to draw on Fricker's theory to understand the use of zines by the survivors I interviewed, necessitates using a much wider definition of hermeneutic resources than Fricker implies. Notably, others have argued for wider definitions of hermeneutic resources (e.g. Crerar 2016; Ferguson 2025) or used definitions broader than the one Fricker (2007) implied (e.g. Shotwell 2017; Kidd and Carel 2018). In addition, Lobb (2018) argues that Fricker's account of epistemic injustice should be expanded to include "implicit, preverbal, affective, and embodied ways of knowing" (p.1).

Testimonial in/justice

As I outlined in chapter 2, survivors' experiences of having our testimony devalued in the mental health system is arguably excluded from Fricker's account of testimonial injustice. However, although Fricker doesn't write about identity as being conceptualised and perceived differently in different contexts, her suggestion that credibility is linked to identity prejudice is useful for reflecting on the significance of what survivors told me about the way in which identity is conceived and perceived as complex within the zine

community. Therefore, although Fricker doesn't explicitly write about identity as complex or multiple, her ideas are helpful to think about how perceptions of survivors' lack of credibility related to their mental health identity might be counterbalanced by positive perceptions of another (aspect of) survivors' identity in the zine community.

Focusing on perceptions of identity led me towards thinking about the way in which survivor knowledge might be perceived as only relevant to survivors, or as Bacevic (2001) might say our knowledge may be seen as bounded to our survivor identity. This in turn was useful for thinking about how survivors might be perceived as knowledgeable about multiple and complex issues because identity is perceived and conceived as complex in the zine community. In order to understand some of the other ways survivors described perceptions of credibility and authority in the zine community it was helpful to draw on ideas about relational authority (Brady, 2001) and vernacular authority (Howard, 2013). This is because sometimes survivors related it to the relationship in which zines were shared, the sense of shared community, or to a culture of valuing non institutional knowledge.

In order to have relational authority a text needs to have been created by a human. In the context of increasing use of automated software and artificial intelligence, being handmade/non digital may increase the authority readers give to a text, as it indicates it has been made by a person rather than, as one survivor put it, a "bot" (automated software). Additionally, humans are able to be *sincere*, and are arguably likely to be more *competent* than artificial intelligence in relation to human experience (Rassaque, 2025). Fricker (2007) argues that sincerity and competence are grounds on which credibility judgements are made.

Testimonial quieting and epistemic oppression and violence

Dotson's (2011) notion of testimonial quieting resonates with survivors' accounts of not being treated as credible knowers in some circumstances and was useful for recognising this as epistemic injustice. Her notion of epistemic oppression was useful for understanding that when survivors expected their testimony to be ignored or devalued by MH professionals in the MH system this may be because there are patterns of survivor testimony being devalued in the MH system. However, whilst Dotson's (2011) notions of testimonial quieting, epistemic violence and oppression are helpful in understanding survivors' experiences, expectations and fears of sharing their testimony in the MH system, they don't help us to understand survivors' responses to these limitations or how we use (can) use zines to work towards epistemic justice.

Tone management/policing

Bailey (2018) argues that marginalised people are epistemically disadvantaged by tone management/policing and, therefore, where anger and knowledge of injustice are entwined, silencing anger involves silencing knowledge of injustice. Bailey (2018) further argues a spiral can be created in which silencing leads to anger, then anger is silenced and with it the knowledge of the injustice of being silenced, which leads to further anger and so on. This is helpful for understanding the significance of some survivors perceiving their anger as unwelcome in the MH system and the significance of survivors choosing to make and share zines which express anger at MH services/professionals, with/in the zine community. It is also helpful for understanding the importance of survivors being able to use hermeneutic resources which enable us to reflect on and articulate our emotions and emotional experiences.

Structural testimonial injustice and testimonial smothering

Anderson (2012) uses the term *structural testimonial injustice* to describe when organisational structures exclude people. Anderson's idea is useful for understanding that the sense of

freedom and control that experienced zinesters associated with zine-making may have been in part due to an absence of being excluded through organisational structures.

Dotson (2011) argues that people evaluate potential audiences and then smother their testimony if they believe that the audience is unwilling or unable to receive it. She further argues that testimony is likely to be smothered if sharing would pose a risk to the testifier, or a group they are a member of, or if the testifier is disadvantaged by the power dynamic between them and the audience.

Dotson's ideas help us recognise that survivors evaluate potential audiences and then respond accordingly. They also help us understand that assessments of an audience's capacity and wiliness to receive testimony, potential risk and power dynamics are likely to inform survivors decisions and actions. In this way, Dotson's ideas help us understand how and why survivors prioritised sharing their zines with audiences whom they expected to welcome them and where they didn't feel disadvantaged by unequal power dynamics or potential risk of harm. Dotson's (2011) account also sheds light on what survivors felt able to reflect on in different contexts. For example, it helps makes sense of why experienced survivor zinesters who had the zine community in mind felt a sense of liberation in relation to what they could articulate in their zines. In this way, Dotson's account helps us understand why making zines with the zine community in mind and then sharing them in the zine community enabled some survivors to articulate and share criticisms, satire and anger that they felt they couldn't articulate and share in the MH system. Dotson's (2011) account of the way in which people assess risk and then alter their testimony accordingly, is valuable in understanding why some survivors employed specific strategies to protect themselves when sharing testimony. Although Dotson (2011) helps us understand that audience and context are likely to be evaluated, and the grounds on which they are evaluated, her work doesn't help us understand the processes by which survivors might evaluate an audience. Dotson's (2011) work helps us understand that if

survivors feel (and are) vulnerable then we will evaluate (and even test) potential audiences. However, it doesn't help us understand why one survivor tried to do this through use of a confusing structure, or how this might compare to other strategies in terms of effectiveness.

Schemata, practice and epistemic systems

Dotson's (2014) writes about what she calls schemata and the ways in which it is (or isn't) reenforced in practice and she writes about what she calls epistemic systems. Her work enables us to think about the ways in which the conditions that shape knowledge production and possession are interlinked. It can also help create a picture of epistemic landscapes, below is an image of how I see her ideas.

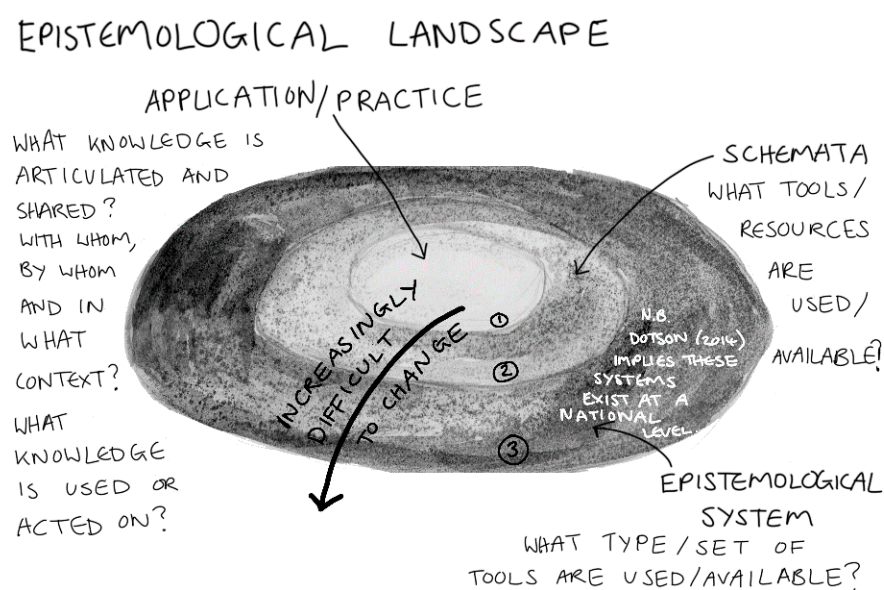


Image 10.1 Schemata, practice and epistemic systems

Dotson (2014) relates schemata to the epistemic tools and resources that are available and the ways in which these are structurally perpetuated. Although Dotson (2014) doesn't define epistemic tools and resources in her example she cites "dominant shared language and instituted social imaginaries" (p.127). With this in mind, you could argue that when creating and

sharing zines in the zine community, survivor zinesters were trying to opt into an alternative epistemic landscape in which the dominant shared language included visual articulation, metaphor and emotion, and a social imaginary in which criticisms of the MH system/professionals can be conceptualised and perceived as warranted and survivors anger is not assumed to be pathological.

Dotson (2014) also writes about the ways in which schemata are reinforced, which is the practice of what knowledge is shared, with whom, by whom and in what context, and what knowledge is used/acted upon. Dotson's account helps us understand that survivors' accounts of their zines being welcomed and valued in the zine community indicates that it is an epistemic landscape in which they are not disadvantaged by the ways in which schemata are reinforced in practice.

Dotson (2014) describes epistemological systems as "our overall epistemic life ways" (p.121). Dotson (2014) refers to epistemological systems as a "holistic concept that refers to all the conditions for the possibility of knowledge production and possession" (p.121). Because Dotson's (2014) description of epistemic systems is very broad it can encompass all the qualities of zines, zine-making and the zine community that survivors described as useful to their process of reflection and articulation. Indeed Shotwell (2017) drew on Dotson's account of epistemic systems when they wrote about hermeneutic resources ranging widely in kind, and including "skills, affect, implicit knowledge, and socially-situated embodiment" (Shotwell, 2017, p. 86).

In relation to my research, it could be argued that the epistemological system in the zine community is one in which survivors expect subjective experience (including emotion) to be recognised and valued as knowledge. In addition, it can be seen as a system in which testimony isn't expected to be linear, where visual articulation can be used to reflect on and articulate experience, and where processes of articulation can help contain emotions and prevent

overwhelm. It is also an epistemic system in which survivor zinesters can be conceptualised and treated as valued epistemic contributors.

Dotson describes epistemic systems as resilient because the elements are interlinked e.g. what we consider to be knowledge, which interpretative resources we use and whose knowledge is valued and utilised, are all connected within an epistemic system. Below is an image depicting the zine community as an epistemic landscape, including the level of application/practice, schemata and epistemological system (image 10.2).

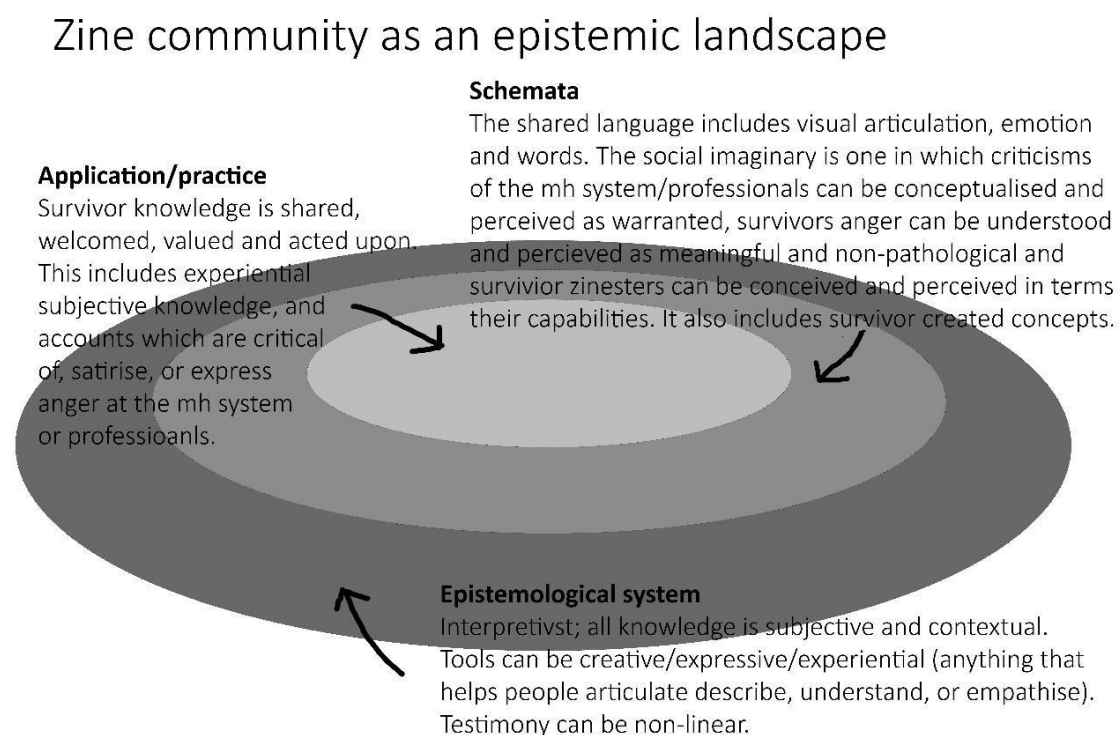


Image 10.2 Relating schemata, practice and epistemic systems to my findings about survivors' use of zines

Dotson's (2014) account of epistemic landscapes is useful for understanding what I discovered about survivors using zines because it helps make sense of the variation of experience survivors described between different contexts. It also helps us to understand that in opting into the zine community some survivors might be opting into an epistemic landscape that works for them on multiple levels. In addition, it creates a model which we can use to contrast the

epistemological landscape of the zine community with the epistemological landscape of the MH system. For example, in the illustration below we can see that the epistemic landscape of the MH system appears to differ in significant ways to the zine community in relation to each level of the epistemic landscape.

MH system as an epistemic landscape

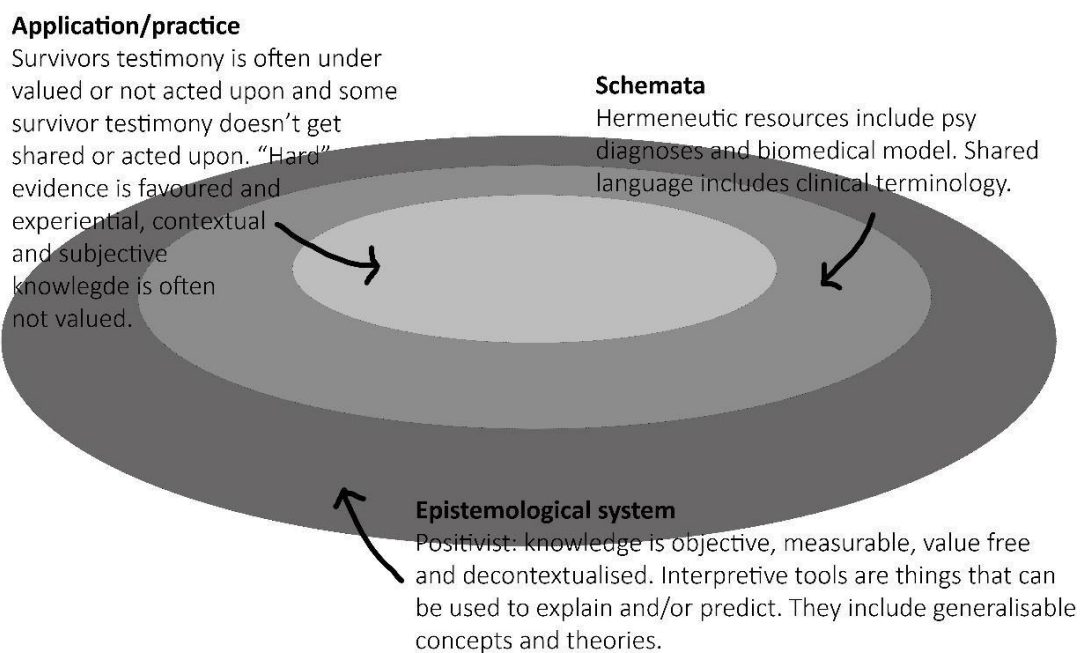


Image 10.3 Relating schemata, practice and epistemic systems to literature about the MH system as outlined in chapter 1³¹

Contributory injustice and wilful ignorance

Dotson's (2012) account of contributory injustice and Pohlhaus' (2012) account of wilful ignorance are useful for thinking about how audiences receive survivors' zines and specifically whether an audience might be relying on the same or different hermeneutic resources or epistemic system to survivor zinesters.

³¹ Much of this literature appears to focus on psychiatry and the psy system however there may be parts of the MH system where the epistemic landscape/system is quite different.

For example, these accounts help us understand that if survivors use survivor-created concepts and subjective experience in their zines, their understandings might be well-received by readers in the zine community because survivor created concepts are in use in the zine community and subjective experience is valued. These ideas also help us understand that if survivors were to share zines which rely on survivor created concepts and subjective experience with audiences who rely on different hermeneutic resources and ways of knowing then their testimony and understanding is unlikely to be recognised or valued. In other words, it's likely to result in contributory injustice (Dotson, 2012) as a result of wilful ignorance (Pohlhaus, 2012).

Dotson and Pohlhaus' ideas also help us to think about why some readers might find it difficult to read and understand non-linear links as interpretive. For example, they help us consider whether this might be due to readers relying on different hermeneutic resources or a different epistemic system to some survivors. In addition, Dotson's (2012) and Pohlhaus' (2012) accounts of contributory injustice and wilful ignorance also help us to understand that, although when shared with other survivor zinesters, visual articulation and sculptural metaphors were effective for communicating emotions and giving reader an embodied sense of survivors' experiences, their experiences might not have been as successfully communicated with a different audience. For example, it helps us understand that communication might not have been as successful if they were shared with an audience who didn't recognise metaphors and images as hermeneutic resources or didn't recognise subjective experience as knowledge. In other words, it helps us understand that if these zines had been shared with in the MH system, for example with psy professionals like psychiatrists or psychiatric nurses, they might not have received the same response.

Dotson's (2012) and Pohlhaus' (2012) accounts also help us understand survivor zinesters' choices of audience. If survivors' sensemaking isn't recognised, we run the risk of our experience being reinterpreted or misinterpreted. Survivors might try to address this through

using hermeneutic and communicative resources an audience favours but which don't work for us, or we might address this through sharing our testimony with an audience who uses and values the hermeneutic resources or epistemic system we have chosen to use.

Dotson (2012) and Pohlhaus (2012) focus on whether people in positions of power recognise the hermeneutic resources created and used by people in marginalised social groups. However, their focus has been on resources created collectively by marginalised people to articulate social experiences, not on how hermeneutic resources might suit neurological or psychological differences and/or enable people to reflect on and articulate the internal experiences of marginalised groups. This is similar to how Fricker focused on people needing hermeneutic resources to articulate social experience. In contrast, I found some survivors used images and visual articulation because it suited how they think, and some survivors described images, visual articulation and/or non-linear structure as important for articulating internal experiences like emotions, dissociation and madness.

This suggests it may be important for survivors to be able to make use of resources which suit how we think and enable us to reflect on and articulate our internal experiences, as well as resources with which we might effectively articulate our marginalised social experience. Survivors may be in a marginalised social position and/or have neurological differences and/or need to articulate our internal experiences, which suggests that in order to understand survivors' experiences of epistemic injustice we may need theories of epistemic injustice that take neurological differences into account and the need to be able to articulate experience. As Bailey (2018) highlights, internal experiences like anger can be related to external experiences like injustice so it is important for marginalised people to be able to articulate our emotional experiences if we are to be able to challenge epistemic injustice. As I outlined in chapter 1, there is evidence that survivors may be more likely to think in images or patterns, and it would be helpful to integrate this into our understanding of epistemic injustice.

Pohlhaus (2012) suggests that contributory injustice can be addressed by a dominantly situated knower recognising, valuing and using resources developed by the marginally situated knower. She writes:

“The dominantly situated knower cannot step outside of her situatedness in order to experience the world as others do; however, she can learn to use epistemic resources developed from the experiences of marginalized knowers” (p.721).

For example, a white person cannot step outside of her whiteness, but she can learn to understand and use concepts developed by people of minoritised ethnicities, (such as the concept of white privilege). Dominantly situated knowers are not necessarily disadvantaged by using such epistemic resources, as it does not make it more difficult for us to understand the world, our own experiences or those of others.

However, if we start to think about epistemic resources and systems that are needed because of neurological and psychological differences, this may become a bit more complicated. This is because in these circumstances dominantly situated knowers (for example, people whose neurology or psychology is seen as standard or desirable) might be epistemically disadvantaged by using resources created and used by marginally situated knowers. For example, if some hermeneutic resources (e.g. images and patterns) are better suited to (some) ways of thinking of survivors whose neurological or psychological differences are pathologised, it's possible that others (who think differently) would be disadvantaged by the use of these resources as they would not offer explanatory power that suits their mode of thinking. This raises questions about how this form of epistemic injustice might be addressed (and possibly what it should be called). In these cases, it might not be fair, reasonable or appropriate to require people who think with words to use images or patterns as epistemic resources, however its equally unfair,

unreasonable or inappropriate to expect visual or pattern thinkers to use hermeneutic resources or an epistemic system that doesn't work for us.

Further understanding survivors' strategies for epistemic justice

Here I outline not just theories but also pictures which I've found helpful to further understand the ways in which survivors might use zines to work towards epistemic justice. Firstly, I outline Dotson's (2012, 2014) idea of Orders of change and how this helps us further understand why survivors chose to opt into the zine community instead of trying to alter the MH system. Secondly, I outline Crerar's (2016) arguments about how taboos can limit people's ability to make sense of their experiences and why an expressively free environment should be considered a hermeneutic resource. I use this to help further understand how community might function as a hermeneutic resource for survivors, to reflect on the role of shame and to consider whether survivors' sense of shame might relate to taboos against naming prejudice. Finally, I outline Archer's (2000) account of agency and use this to help further understand the way survivors created and shared zines with trusted audiences as a part of a practice of social reflexivity and alliance building.

Orders of change

This section explores how Dotson's (2012, 2014) idea of Orders of Change helps us further understand why the survivors in my research chose to opt into the zine community instead of trying to directly engage with the MH system. Dotson (2012, 2014) describes three different types of epistemic injustice which she calls first, second and third order epistemic injustice. In practice, these injustices are not easy to delineate, but thinking about them in this way can shed light on how epistemic justice might come about.

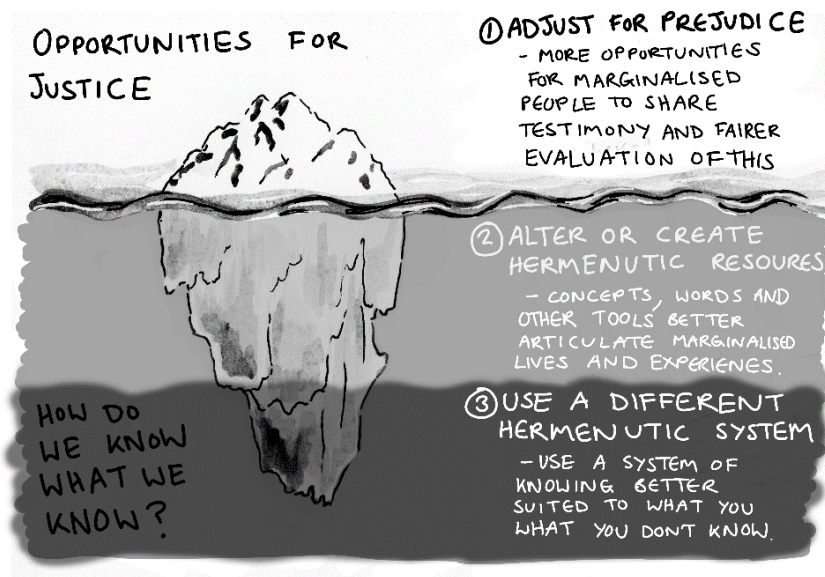


Image 10.4 Orders of change

If epistemic injustices can be addressed through improving an audience's ability to render more accurate credibility assessments, then Dotson (2012) would describe the injustice as first order epistemic injustice. First order epistemic injustice is perpetuated by individual agents, and therefore can be addressed through individual agents working within established frameworks. An example of first order injustice might be a professional devaluing a survivor's testimony due to relying on prejudiced stereotypes relating to a person's psychiatric diagnosis and first order change would involve that professional adjusting their prejudicial stereotypes when evaluating their testimony, i.e. awarding survivors authority despite the stereotypes. Fricker's (2007) account of testimonial injustice would come under this definition. As outlined in the previous chapters, it has been suggested that survivors would benefit from MH professionals learning to listen better (Crichton *et al.*, 2017) and not stereotyping survivors' beliefs as necessarily lacking insight or delusional (Sanati and Kyratsous, 2015). In other words, although these writers don't refer to Dotson's work about orders of change, they suggest that survivors would benefit from individual audiences' practices changing.

Where injustice needs be addressed through changing structures and frameworks, Dotson calls this second order epistemic injustice. Fricker's (2007) account of hermeneutic injustice might fit

under this definition. Second order epistemic injustice is structurally perpetuated and includes injustice which needs to be addressed through seeking out and changing the socio epistemic conditions and values within the structure which foster hermeneutic injustice. You could say this is about the epistemic resources that are available and valued in an epistemic system or landscape. An example of second order injustice might be when the conceptual resources needed by survivors aren't available in the MH system. Although Dotson doesn't say this, you could argue that if the conceptual resources relied on in the MH system prevent survivors from being seen as credible knowers. this is second order epistemic injustice. An example of second order change might be changing the structure and culture of the MH system in such a way as to include interpretive resources that have been developed by and for survivors. This might include things like incorporating therapeutic tools that survivors have created or been involved in developing like the Power Threat Meaning Framework (Johnstone and Boyle, 2018) and Dialectical Behavioural Therapy (Linehan, 2014), or it could include survivors' being involved in the development of diagnostic tools as Kurs and Grinshpoon (2017) have suggested.³²

Finally, where injustice needs to be addressed through having fluency in a range of differing sets of interpretive resources and being able to shift between these, Dotson (2012) calls this third order epistemic injustice or *contributory* injustice. This type of injustice is caused by both structurally prejudiced hermeneutical resources and individual's actions in deciding which sets of hermeneutical resources to use. Dotson's account of third order epistemic injustice is based on a recognition that we do not all depend on the same sets of interpretive resources and that injustice occurs when people don't recognise, value or use "the necessary tools for knowing whole parts of the world" (Pohlhaus, 2012, p.729). A third-order change "requires perceivers to

³² I give these examples because they might involve changes to the structure and culture of the MH system but would not necessitate changing the whole epistemic system on which they rely. For other survivor created resources to be incorporated might necessitate more fundamental changes to the epistemic system.

be aware of a range of differing sets of hermeneutical resources in order to be capable of shifting resources appropriately” (Dotson, 2012, p.34).

An example of third order epistemic injustice might refer to situations where survivors develop and use alternative interpretive resources outside the MH system, but MH professionals don’t take them on board as it would involve them moving away from the set of interpretive resources they have come to rely on in the MH system, despite these being inadequate for understanding survivors’ experiences. In this context, an example of third order change might be where a professional recognises the value of an image a survivor uses to make sense their experience, or recognises the value of a concept like sanism³³, despite these not fitting into the prevailing epistemic system relied on in the MH system.

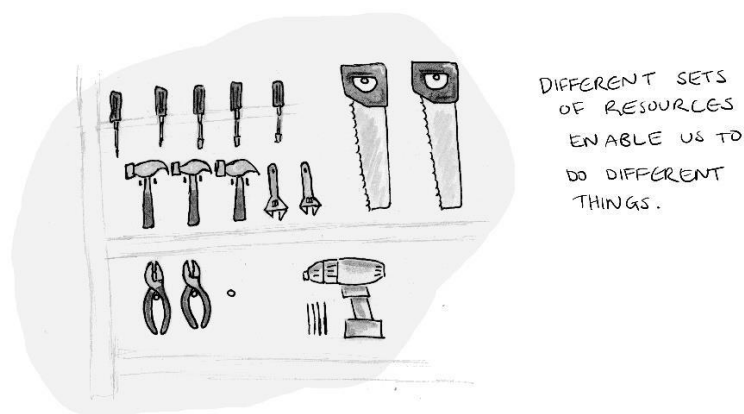


Image 10.5 A set of tools for a type of work/purpose

According to Dotson, third order epistemic injustice is caused by:

“an epistemic agent’s situated ignorance, in the form of wilful hermeneutical ignorance, in maintaining and utilizing structurally prejudiced hermeneutical resources that result in epistemic harm to the epistemic agency of a knower. Both the structurally prejudiced or biased hermeneutical resources, and the agent’s situated ignorance, are catalysts for

³³ Sanism might be difficult to incorporate into an epistemic system which, arguably perpetuates this form of oppression, by focusing on what might be ‘wrong’ with an individual and how this might be treated.

contributory injustice. As such, it is located within the gray area between agential and structural perpetuation of epistemic injustice” (Dotson, 2012, p.31).

In other words, it is not that other epistemic resources and systems aren’t available, but that these resources and systems are not recognised by the audience. This means that whilst people may be able to reflect on and articulate their experiences, the audience in question will not recognise the knowledge because they don’t recognise the resources that have been used to articulate it. This fits with what we know of many survivor’s experiences in the MH system where, as I described in chapter 1, survivor-developed concepts often go unrecognised (Le Blanc and Kinsella, 2016), survivors are disadvantaged by MH professionals reliance on the diagnostic system and medical model (Hassall, 2024; Harper, 2019; Grim *et al.*, 2019; Wodziński and Moskalewicz, 2023) and more fundamentally by the ontology and epistemology MH professionals rely on (Crichton *et al.*, 2017; Carel and Kidd, 2014; Scrutton, 2017; Rose and Kalathil, 2019; Florsheim, 2020; Jackson, 2017). Indeed, as I outlined in chapter 1, it has been argued that survivors would benefit from MH professionals using a subjectivist epistemology and a more phenomenological approach (Carel, 2012; Ritunnano, 2022; Parnas *et al.*, 2013; Jackson, 2017). In other words, it is suggested that survivors make use of what Dotson might call an alternative epistemic system.

Dotson’s ideas about orders of change help us understand the changes that might help address the epistemic injustices experienced by survivors in the MH system. However, survivors do not have the power to change the way individuals in the MH system respond to our testimony, we can only seek out individuals we believe might not devalue our testimony. We have limited (if any) opportunities to shape which hermeneutic resources are available and valued e.g. we cannot change which diagnostic tools, models or frameworks are used. Understanding how difficult it is for survivors to affect change in the MH system helps us further understand why survivors might opt into an alternative epistemic environment.

Dotson's ideas about third order change help us understand that while survivors might benefit from engaging with an alternative epistemic environment like the zine community, it will be difficult to communicate knowledge developed from this environment with MH professionals who are operating within a different epistemic system because this would require professionals to be aware of, see the value of, and step into a completely different way of knowing/epistemic landscape/system. This helps us understand that, whilst survivors cannot make third order change happen on our own, we might create opportunities for it to happen, for example by making use of an epistemic system that works for us and then sharing our understandings others including MH professionals, as some survivors did.

Dotson argues that ways of preserving and legitimising sets of epistemic resources are built into what she calls epistemic systems. She suggests it is difficult for us to perceive epistemological systems as we are in them and so they shape what we can know. In other words, to perceive and question our epistemic system is akin to questioning the fabric of our world. It involves questioning what we think we know, what we think we can know, and how we think it is possible to know. If we relate this to survivors' experiences of epistemic injustice, we can understand why it can be incredibly difficult for MH professionals to step outside their epistemic landscape and consider the benefits of alternative epistemological systems, such as ways of knowing that are based on survivors' experiences and interpretations or alternative systems which enable these to be articulated. In this way, Dotson's account helps us understand how difficult it will be for Psy professionals who are steeped in the epistemic landscape of the MH system to recognise the limitations of this landscape, and this helps us further understand why survivors didn't prioritise MH professionals as an audience.

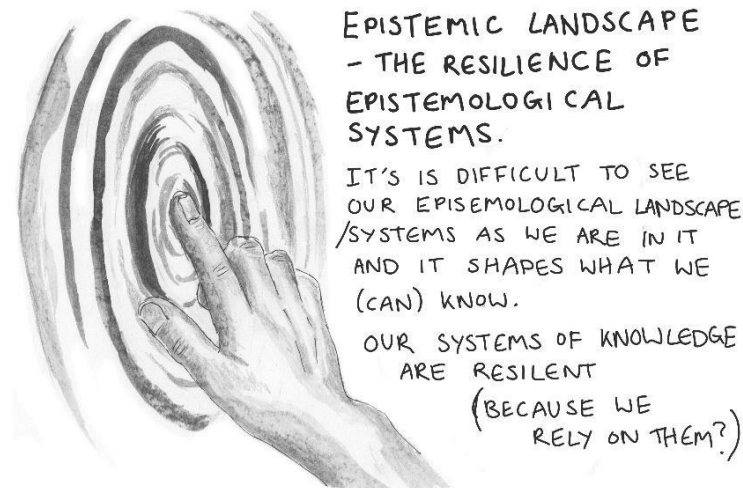


Image 10.6 Inability to see the system from within

Bailey (2014) argues that “the biggest obstacle for epistemic liberation (the one Fricker misses) is that our shared epistemic resources are themselves *inadequate* for understanding their inadequacy (p.66, emphasis in the original). Responding to Dotson’s work, she argues that changing third order epistemic injustice requires a broader understanding of what constitutes epistemic resources. Drawing on Bartunek and Moch (1994) Bailey suggests that to create third order change we must engage creative and affective interpretive resources. She acknowledges that whilst Dotson doesn’t give the example of creative and affective interpretive resources, they are not excluded from her definition of third order change. Given that it was important for some survivors to be able to use creative hermeneutic resources to articulate and share emotional experiences like anger about injustice, Bailey’s (2014) argument that third order injustice might be addressed through engaging creative and affective interpretive resources rings true. Perhaps the key is understanding whether marginalised groups tend to benefit from epistemic systems in which creative and affective interpretive resources are used and valued, as survivors in my study appear to and, if so, whether third order epistemic injustice might be addressed by dominantly situated people recognising and valuing these resources.

Therefore, Dotson's (2014) ideas about orders of change help us further understand why survivors might be drawn to alternative epistemic landscapes and systems. They help us understand what the zine community might offer marginalised knowers like survivors, why marginalised knowers might develop and share understanding in the zine community, and the difficulties they might experience sharing these understandings outside the zine community. The following section explores an example of how a social context might serve as a hermeneutic resource.

Taboo and expressively free environments

This section explores how taboos can limit people's ability to make sense of their experiences and why an expressively free environment should be considered a hermeneutic resource (Crerar 2016). I use this to consider whether survivors' sense of shame might relate to taboos against naming prejudice and to help further understand how zine community might function as a hermeneutic resource for survivors.

Crerar (2016) argues that taboo shapes how and whether interpretive resources can be used to make sense of experiences. They further argue that "an expressively free environment in which to discuss a particular subject has an important role to play as a *hermeneutical resource*" (my emphasis, Crerar, 2016, p.196). This aligns with the way the imagined community that survivors had in mind appeared to shape what they felt able to reflect on and articulate in their zines.

Crerar (2016) argues that context is important for making sense of experience and hermeneutic injustice isn't always caused by an absence of interpretive resources as Fricker describes.

Crerar (2016) notes that although Fricker describes people developing and using concepts which enabled them to describe experiences that had previously been difficult to describe, she doesn't pay sufficient attention to the particular contexts which enabled them to do this. For example, she didn't sufficiently explore what it was about the context of a women's consciousness raising group that enabled the term sexual harassment to be coined and used.

Crerar (2016) argues that having a significant area of experience treated as taboo “can have a hugely detrimental impact on how one comes to interpret the experience” (p.201). They argue this is because taboos can prevent people from using interpretive resources. Crerar (2016) suggests this is because where there is a taboo there can be a personal and social costs to applying interpretive resources which can result in the experience of shame. They give the example of women and girls having information about menstruation, but being unable to apply this and properly understand their experience in environments where menstruation is taboo.



Image 10.7 The costs of taboos

Crerar’s (2016) emphasis on the epistemic limitations caused by cultural taboos, resonates with how I’ve described survivors making and sharing zines as unshaming in the context of negative identity prejudice and social injustice. Using Crerar’s ideas, we might suggest that this is, at least in part, because there are taboos in some environments against naming the prejudices and injustices that survivors referred to. For example, we might question whether there is a social cost to calling an experience sanist or using the term mad pride.



Image 10.8 Taboo and use of conceptual resources

Moreover, Crerar (2016) argues that in order to make sense of experience “we require access to an expressively free environment in which to put ... concepts to work: an open and receptive social context in which a particular experience that individuals or groups have a significant interest in coming to understand can be discussed in hermeneutically conducive ways” (p.205). Crerar’s account of an expressively free environment resonates with the ways in which survivors who were familiar with the zine community described a sense of freedom when creating their zines. It also helps us understand that zines may contain conceptual resources created by survivors, or images and non-linear structure to interpret experience, partly because these are not taboo in the zine community.

This understanding leads us to identify, explore and maybe challenge environments in which taboo and shame play a role in inhibiting the use of these interpretive tools. In addition, as some survivors used zines as a creative object to create distance between themselves and testimony they felt might be taboo, there may also be scope to explore the ways in which people try to protect themselves from the social cost of articulating and sharing their testimony. Whilst there is art therapy literature about how art objects can create distance between the creator and what they are communicating and might enable people to share things they might not be able to

otherwise (Dalley *et al.*, 1993; Haeyen, 2018; Johnson, 1987), I can only find one reference to zines (Clacherty, 2024). In addition, this hasn't previously been written about in relation to epistemic injustice.

If cultural taboos prevent knowledge being articulated and shared, they need to be part of the conversation about survivors' experiences of epistemic injustice. Perhaps we need to research which knowledge, concepts and sensemaking resources/processes may be taboo within services, which taboos are disadvantaging survivors, how these taboos are maintained and how they might be changed. Through making and sharing zines, individual survivors can be described as enacting agency at intra and interpersonal levels. In the next section I explore agency more detail.

Survivor zine-making as agency

In making their zines, survivors made choices about how they define their concerns, understandings and perspectives. At times this involved questioning social conditioning, and stepping away from, or questioning, the ways survivors are expected to perceive and act in the MH system. Through sharing their zines survivors might have influenced the perspectives available to their readers and/or readers actions. In addition, some survivors thought engaging in social reflexivity through making and sharing zines, or developing a sense of shared concern through shared zines, might be seen as a step towards collective action and influence.

To understand how survivors used zines to express their agency, I have found it useful to engage with Archer's framework for thinking about agency (Archer, 2000). This helps understand that whilst relatively enduring patterns of injustice and inequality can be hard to change, people (in this case survivors) nonetheless have some power within these contexts. I also found Archer's account of agency useful to further understand the way survivors created and shared zines with trusted audiences as a part of a practice of social reflexivity and alliance building.

Archer (2000) suggests that the degree of influence people can exert in the social world relates to the extent to which people can organise around a shared interest, and pull together the necessary resources to help achieve this interest and to have an impact on wider social conditions. When a group of people achieve this level of organisation, she describes it as corporate agency. In the Collins dictionary one definition of corporate is: “of or belonging to a united group; joint”. Corporate agency is not just about what corporations achieve; it also applies to social movements.



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Image 10.9 Corporate agents

At the same time, Archer acknowledges that people who share patterns of dis/advantage but cannot organise for shared interests, nonetheless achieve some agency in dealing with, accommodating to, and adjusting their environments. She refers to these as *Primary Agents*. Primary Agents don't act strategically as a co-ordinated group with shared interests, and until they move into a more organised and cohesive form they don't have shared resources with which to act. Therefore, in primary agency, (social) conditions tend to persist as they are, and wider systems remain unchanged. This resonates with the way in which some survivors said

³⁴ Despite what this image may suggest, being a corporate agent doesn't necessitate wearing office wear!

that they didn't expect to have wider influence, but they valued the influence they might have on a single reader.

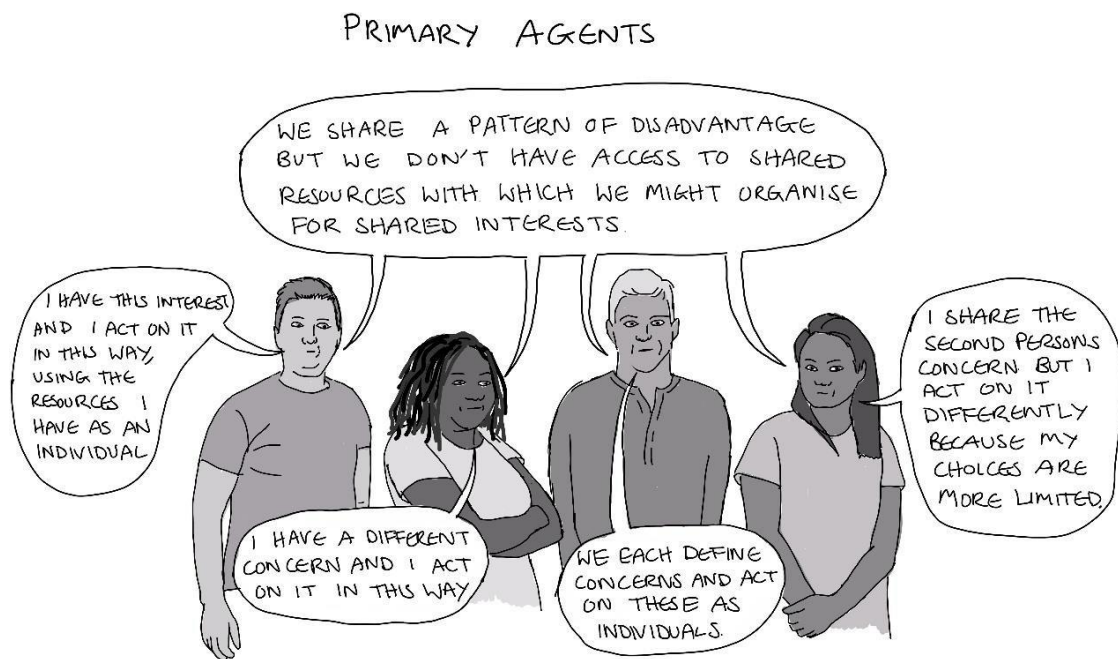


Image 10.10 Primary agents

Although some experienced survivor zinesters described acting proactively and with intent when choosing their audiences, they were not doing so as an organised collectivity and so, by Archers (2000) definition, they would be described as Primary Agents.

Although survivors described engaging in social reflexivity through collaboratively making zines, or through sharing, reading and responding to zines they still fit Archer's (2000) description of Primary Agents because they weren't engaging in action as a collectivity and there was no indication that they had access to resources with which they could collectively and strategically articulate shared interests, organise and engage in action. However, by engaging in a social process of reflexivity, and in trying to collaboratively and collectively define concerns they could be described as attempting to move away from Primary Agency towards Corporate Agency. In other words, we might understand the ways survivors chose to engage in social reflexivity, and used zine sharing to recruit allies, as attempts to create the possibility of collective action.

Through engaging with the zine community, creating, sharing their zines away from the MH system and in the zine community, with other survivors or with other welcoming audiences, survivors might be described as creating, building or gathering hermeneutic resources. These actions were used as ways for survivors to: develop epistemic confidence; access and use survivor created language and concepts; gain awareness of survivors (shared) experiences and concerns; recognise that there are cultures that differ from that of the MH system; access and use creative, visual and non-linear forms of articulation; and develop the ability, and opportunities, to see themselves and their perspectives as unshameful. These resources can be used to benefit individual survivors, but the process of creating, building or gathering them in a social context might also be described as a way of moving towards corporate agency and the possibility of system change.

Summary

To draw on Fricker's account of hermeneutic injustice in relation to what I discovered about survivors' use of zines, necessitated using a much broader definition of hermeneutic resources than Fricker implies (2007). Supplementing Fricker's (2007) account of hermeneutic injustice, with Dotson's (2012) account of contributory injustice and Pohlhaus's (2011) account of wilful ignorance helps understand which hermeneutic resources are available to survivors, which hermeneutic resources are recognised by audiences, and how this can shape what survivors can reflect on, articulate and communicate. These theories help to understand which aspects of zines and the zine community survivors drew on to reflect on and articulate their experiences and whether different audiences might respond differently to the resources and processes survivors used. They help us understand that whilst visual and sculptural qualities helped survivors communicate their experience and emotions to other survivor zinesters in the context of this study, they might not help them to do this in other contexts.

Together, Fricker's (2007) idea of testimonial injustice, along with Bacevic's (2001) concept of bounding, Brady's (2001) idea of relational authority, and Howard's (2013) idea of vernacular authority are helpful for understanding some of the complexity of how testimony in the zine community is evaluated. In addition, Anderson's (2012) theory of structural testimonial injustice and Dotson's (2011) account of testimonial smothering help us understand that organisational structures and expected audience responses can limit what survivors can share or what they feel able to share. Absence of structural exclusion and a welcoming audience might account for the way survivors who were familiar with the zine community described a sense of freedom and control in relation to their zine-making and the content of their zines.

Furthermore, Bailey's (2018) account of tone management/policing helps us understand the importance of anger and why survivors choose to share anger in the welcoming space of the zine community as opposed to the MH system. It also helps us understand why it might be important for survivors to have access to resources which help them to reflect on and express emotions which might link to wider experiences of oppression.

Moreover, Dotson's (2011) accounts of silencing, epistemic oppression and epistemic violence help us understand that survivors' expectations of audiences in the MH system might be related to patterns of silencing. Dotson's (2011) account of testimonial smothering also helps us to understand that survivors will evaluate potential audiences' willingness and ability to receive testimony, and the risk that sharing with a particular audience might pose, and then use strategies in response to their assessment of an audience.

These theories are all useful for understanding that power dynamics and risk will relate to survivors' assessment of potential audiences. They help us think about the difference between contexts in which there are patterns of silencing and contexts in which silencing might be harmful. In particular, they help conceptualise the motivation behind survivors' strategies and

why survivors might choose to share zines away from the deeply unequal power dynamics of the MH system.

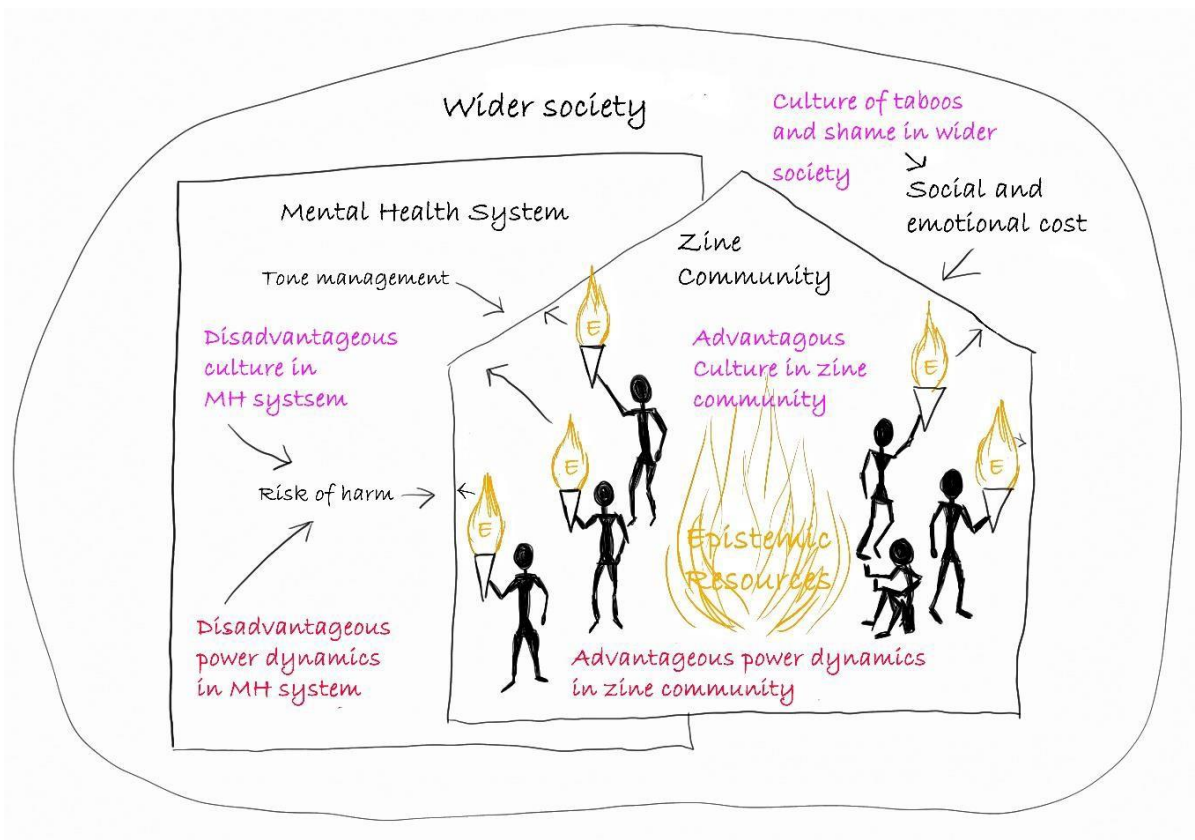
Dotson's (2014) account of epistemic landscapes helps us to understand the links between which testimony can be shared and taken on, which hermeneutic resources are available, and the other conditions that enable or disable the production and possession of knowledge (e.g. beliefs about what knowledge is valued and how we can know things). It also helps us to think about how the epistemic landscape of the zine community compares to that of the MH system. This, combined with her account of orders of change and the resilience of epistemic systems, helps further conceptualise why access to the zine community may be important to survivors and why survivors opt into alternative epistemic environments. For example, making and sharing zines enables survivors to opt into an epistemic landscape in which their testimony is valued and they benefit from being able to engage with a range of hermeneutic resources to reflect on and articulate and share experiences. In addition, Crerar's work helps us to understand the relationship between taboo and shame and how cultural taboos might make it difficult for survivors to reflect on, articulate and share experiences and challenge epistemic injustice.

Finally, I drew on Archer's (2000) account of agency to understand the challenge survivors face trying to effect system change when acting alone. Through engaging in social reflexivity via their zines, survivors might be taking steps to exercise collective agency, or what Archer calls corporate agency. Whilst Archer doesn't connect her ideas to epistemic injustice, if acting as a corporate agent makes system change possible, it might also make it possible to affect the hermeneutic resources that systems (like the MH system) rely upon, and therefore move towards epistemic justice...

Together these theories help us understand how and why survivors in this study used zines in the ways they did. In particular, they help us understand much about how survivors' epistemic

activities can be limited for example through creative, visual and structural hermeneutic practices/resources being unrecognised/unvalued in some contexts. They also help us to understand and appreciate the motivations behind the strategies survivors use and the opportunities afforded to survivors by zines and the zine community.

To bring ideas about culture, freedom and harm together with ideas about epistemic resources and to locate survivors' experiences and strategies in the landscapes described by them and in the literature about epistemic injustice in the MH system, I created the image below (image 10.11). This image draws on Dotson's ideas about risk and harm when sharing testimony, Crerar's work about the significance of taboo and Bailey's ideas about tone management/policing. It brings together what I've learned about survivors' experiences of power dynamics and culture in different settings and the way in which survivors accessed, gathered and developed epistemic resources within the zine community. It shows how, by building the fire of epistemic resources (shown in the safe environment at the heart of this image) survivor zinesters can carry the light of understanding that can be used by others outside of this space.



Filmage 10.11 Culture, power dynamics and epistemic resources

Culture

Advantageous Culture in Zine

Community: Anger is acceptable/welcome; being survivor is not shameful; Survivors can be seen in terms of our strengths; Complex intersectional experiences are recognised/valued.

Disadvantageous Culture in MH System:

Anger not welcome; survivors perceived as only mad/service users; survivors devalued as knowers, rely on concepts created by and for MH professionals; non-linear thinking is perceived as pathological.

Culture of Taboos and Shame in Wider

Society: taboos about bereavement, therapeutic relationship, being care experienced; shamed for being mad/in receipt of services, being a person of colour, being older, being a woman, being disabled, being queer, being a victim of violence/abuse

Power dynamics

Advantageous Power dynamics in Zine Community:

Survivors are free to control how our experiences are reflected on and articulated and how experiences and understandings are shared, and it is safe(r) to share criticism of/anger at the MH system

Disadvantageous power dynamics in MH System: Deeply unequal power dynamics with professionals able to make decisions about survivors' treatment and autonomy; agenda set by professionals/systems; criticism of r anger at MH services/professionals is unwelcome and goes unshared.

Epistemic resources (E)

Creative, visual and structural sensemaking resources and practices; Epistemic confidence; survivors created concepts, awareness of shared experiences and concerns; creative visual and non-linear forms of articulation; awareness that there are cultures/perspectives that differ from that of the MH system; the ability to see self and perspectives as unshameful

Survivors may have felt able to access, gather and develop epistemic resources in the zine community because it is a community in which we are free to control how our experiences are reflected on and articulated and how experiences and understandings are shared, as well as it being safe(r) to share criticism of/anger at the MH system. They may also have felt able to do this because it was a culture in which our anger is acceptable/welcome, being survivor is not shameful, it's possible to be seen in terms of our strengths, and complex intersectional experiences are recognised/valued. In other words, the power dynamics and the culture together may have been important to facilitating this.

Conclusion

This chapter summarises what I've learnt from this study. First, I identify the gaps in knowledge identified through my literature review and reflect on the research methods and methodology I used to address these gaps. I then summarise what I've learnt from this study about how survivors use zines to address epistemic injustice and use this to identify areas for further research. I then outline some implications for practitioners and finish with some personal reflection on the process of conducting this study.

Gaps in literature

My review of the literature about survivors, zines and epistemic injustice revealed a wealth of literature about survivors experiencing epistemic injustice in the mental health system but very little literature about survivors' experiences outside the mental health system and very little literature about how survivors respond to all this or try and address it. Similarly, whilst there is literature which indicates that zines and the zine community might provide advantages for articulating and sharing survivor knowledge there is limited literature about how, why and to what effect survivors use zines and the zine community to address epistemic injustice. Specifically, there is very little literature about how making and sharing zines might support survivors to reflect on and articulate our experiences and then share our understandings.

Moreover, whilst theories of epistemic injustice have been increasingly applied to survivors, they haven't been widely applied to zines (and survivors' uses of them). This study addressed these gaps in knowledge by designing and carrying out a survivor-centred and zine-centred piece of research about survivors' uses of zines. I applied theories and concepts relating to epistemic injustice that have not been extensively applied to survivors, let alone survivors' zine-making and sharing.

Reflections on my methods and methodology

I developed a bricolage methodology drawing on a combination of (critical) participatory action research, autoethnography, arts-based research and narrative research. My methods were unique, experimental and innovative in that, as well as gathering data through zine-making sessions, I used zine-making methods in my process of analysis. Whilst zine making has been used in other studies as a method of *data collection* (Cameron, 2012; Ptolomey, 2020; Weisser, 2018) and as a way of *sharing research findings* (Covid realities, 2021; Tantam *et al.*, 2024) I found only one example of zine making being used as a method of *analysis*. (Biagioli *et al.*, 2021). Biagioli *et al.* (2021) focus on individuals making zines as part a personal process of reflecting on experiences like conference attendance, or to express a problem they were investigating (for example as part of their MA study), which is similar to the autoethnographic reflective zine making I have done throughout this study. They also share a more detailed account of using zine making to bring together key ideas from a networking session, which is similar to my thematic zine making analysis. However, their process differs in significant ways from my zine-making-as-analysis processes. For example, their analysis didn't involve bringing together and analysing different types of data (e.g. transcripts, zines and field notes) and none of their zine-making drew on narrative analysis.

Like other creative researchers (e.g. Hodges 2024), I found that using arts-based research methods strengthened my relationship with participants. The responses I received from participants with whom I shared my analysis zines were all very positive; they seemed to have found the medium both accessible and engaging and sharing the zine with them appeared to strengthen our relationship.

Like Barratt (2024), I found drawing helped me to engage with emotional experience within workshops and in response to zines. For example, I found creating images helped me reflect on and capture the uncertainty I and other readers felt on engaging with Bex's padlocked zine; the

discomfort I feel when expected to identify according to a single criteria; the confusion and frustration I felt when I struggled to understand Nazrah's images, and the sense of joy and freedom some participants expressed in relation to making and sharing their zines.



Like Neilson and Kenny (2024) and Gascoine *et al.* (2024), I found that visual methods helped me to compare different sets of data, reflect on commonalities and differences and identify themes.

Participants would usually be considered co-investigators throughout a Participatory Action Research (PAR) process (Gillis and Jackson, 2002) and I would have preferred to engage participants in the meaning-making process throughout my study as it is a good way to share power, as well as a way to achieve a systematic and robust analysis (Brown, 2024). Additionally, research on the experiences of survivors of colour and disabled survivors should ideally be carried out by people in these groups and, although I am a survivor, I am not a person of colour or disabled. My ability to involve participants in my analysis was limited by this research being part of my PhD; if the other participants in this study were to have conducted the research and analysis, then the work could not have formed part of my thesis. Instead, I created a process in which participants had some influence over the process, but I then reflected on and analysed

what they told me about the process. In this way, participants from Stage One were able to influence what was included as data (zines as well as interviews), and some aspects of the Stage Two process (focusing on marginalised survivors, and participants choosing the topic of their zines), whilst participants from Stage Two directed the zine making and sharing process they took part in. However, participants didn't have influence over other aspects of the research. It is not ideal, but I had to work within the constraints of doing a PhD. After I have completed the thesis, I will send participants a zine summary and include any feedback/comments in publications arising from the PhD. In this way, I will ensure participants priorities and observations are given a platform.

My research is based on a small number of participants who are unlikely to be representative of survivors in general. So, whilst I can draw conclusions about how and why the survivors in my study made and shared zines, and how they use zines to try and address epistemic injustice, these findings may not be widely applicable. Given my method relied on a lot of my own reflections and insights, the research isn't easily replicated and doesn't lend itself to large scale studies and widely generalisable understandings. However, that is not the intention of such in-depth qualitative research.

Conclusions and scope for further research

Here I outline what I discovered about how survivors in my study used zines, applying theories of epistemic injustice and Archer's notion of agency, and draw on my findings to make suggestions for further research.

Making and sharing zines afforded survivors a variety of opportunities which they found helpful in relation to reflecting on and articulating experiences, and in relation to communicating experiences and understandings. In other words, zine making and sharing enabled some survivors to produce and share knowledge and, in this way, to address epistemic injustice. The opportunities making and sharing zine afforded related to the qualities of zines and zine-making

and the qualities of the zine community. To understand the opportunities zine-making and sharing offer and how they might be used to address epistemic injustice necessitated using a very broad definition of hermeneutic/epistemic resources. It also involved drawing on Dotson's account of epistemic landscapes to think about the way in which the conditions related to knowledge production interact. In this way it was possible to see how the opportunities that making and sharing zines afford survivors are interlinked. Given how useful this expansive approach was to understand survivors' experiences of using zines, there may be scope to use Dotson's (2014) model to more extensively explore the conditions of epistemic systems that survivors find beneficial, and to use this to explore survivors' experiences in the MH system or other settings in more depth.

Survivors used zines, zine-making and the zine community to engage in protective strategies; engage in shared sensemaking, social reflexivity and/or alliance building; and to access or develop resources which might support reflective processes. Whilst I found that my participants engaged in a range of strategies through their zine-making and sharing, it is not possible to know whether these strategies are widely used by survivors. Therefore, there is scope for further research into the strategies survivors employ to combat epistemic injustice. I outline below some of the questions my study raises about survivors' strategies.

Drawing on Dotson and Pohlhaus's notions of contributory injustice and wilful ignorance to understand survivors' use of epistemic resources raises questions about how epistemic injustice might be addressed if people's need for particular epistemic resources is based on neurological or psychological differences. Therefore, there is a need to further explore the relationship between neurological and psychological differences, epistemic resources and epistemic injustice. There is especially a need for research that focuses on how epistemic injustice rooted in neurological and psychological differences might be addressed, because it

cannot be addressed in the way that Dotson and Pohlhaus suggest contributory injustice might be addressed. For example, if some hermeneutic resources (e.g. images or patterns) are better suited to people who are neurodivergent or have psychological differences, it's possible that others (who think differently) would be disadvantaged by the use of these resources. Therefore, it might not be possible or appropriate to try and address this injustice though requiring others to make use of these resources.

In these cases, it might not be fair, reasonable or appropriate to require people who think with words to use images or patterns as epistemic resources, however its equally unfair, unreasonable or inappropriate to expect visual or pattern thinkers to use hermeneutic resources or an epistemic system that doesn't work for us.

I discovered that survivors engage in protective strategies. These included: using the zine to create distance between themselves and their testimony; sharing implicit (instead of explicit) interpretations; testing readers' commitment; and creating and sharing testimony in/with welcoming and safe(r) communities/relationships. I also discovered some survivors experienced their testimony being ignored or devalued in the mental health system, or expected that they would experience this, and some thought that sharing (angry or critical) testimony in the mental health system would have negative/harmful consequences. Survivors' negative experiences and expectations of sharing testimony in the mental health system, along with Dotson's notion that people evaluate potential audiences and the risks of sharing testimony, and her account of the resilience of epistemic systems, help make sense of survivors' use of protective strategies. However, there is scope to further explore and evaluate the effectiveness of the protective strategies that survivors might employ in response to epistemic injustice. Specifically, there is a need for further research into how survivors might most effectively and productively evaluate (or test) potential audiences; how professionals who are willing and able

to hear might demonstrate this; and how services might reduce the risk (and perceived risk) associated with survivors sharing testimony in the MH system.

I discovered survivors engaged in shared sensemaking, social reflexivity and alliance building through creating and sharing zines away from the mental health system. Dotson's account of the reliance of epistemic systems makes sense of survivors' choice to opt into alternative epistemic landscapes, whilst Archer's notion of agency indicates that engaging in shared sensemaking, social reflexivity and alliance building, might be a route to survivors having wider social influence. However, there is a need for more research into the processes through which survivors might become what Archer calls corporate agents, and the effectiveness of this strategy. Drawing on the image I created, that brings my findings about culture, freedom and harm together with survivors' development of and access to epistemic resources (image 10.11), there is also scope to further explore the relationship between culture and power dynamics, and survivors' experiences of epistemic resources and practice. Finally, making and sharing zines can help survivors address epistemic injustice through directly enabling us to develop and share knowledge. It can also enable us to gather, build and access epistemic resources which, in turn, can be used to tackle epistemic injustice. However, it is not possible to say how much influence these strategies might have, directly or indirectly, on survivors' experiences of epistemic injustice in the mental health system. For these strategies to have influence in the mental health system, mental health professionals would have to be able and willing to look outside the epistemic system on which they rely, as well as to change their practice to incorporate survivor created hermeneutic resources into the set of epistemic tools on which they rely. I suspect it would also require that mental health researchers were open to recognising the value of a wide range of sensemaking resources, systems and practices. Going forward, there are multiple ways in which we might further explore survivors' experiences of epistemic (in)justice in the mental health system and the effectiveness of survivors' strategies.

Implications for practitioners

Practitioners have an important role to play in addressing the epistemic injustice survivors

face. For example, we may benefit from reflecting on the epistemic landscape in which we are working. This includes reflecting on who can share knowledge and how this is responded to, and considering what hermeneutic resources might be more or less available and appropriate to survivors, as well as their advantages and disadvantages. For example, recognising that people with neurological or psychological differences may benefit from using alternative hermeneutic resources (e.g. images and patterns) and, where possible, utilise and facilitate the use of these resources, and not rely on resources that might disadvantage people with these differences or preferences. It also includes questioning our perceptions about what counts as knowledge and how we can come to know about the world, specifically reflecting on how this shapes our understandings and assumptions. In terms of practice, practitioners can then build on this by demonstrating that we welcome and value a range of testimony and hermeneutic resources and tools.

Even in the absence of systematic changes to power structures, professionals could attempt to reduce the smothering of survivors' testimony and the (perceived) need for survivors to employ protective strategies. We can do this by working towards creating an environment in which it is and feels safe(r) or less risky for survivors to share testimony, especially critical and angry testimony. This might include communicating, demonstrating and ensuring that sharing testimony doesn't result in negative consequences for survivors (for example support or the involvement opportunities will not be withdrawn). It might also include inviting criticism, acknowledging anger and acknowledging the experiences on which these reactions are based.

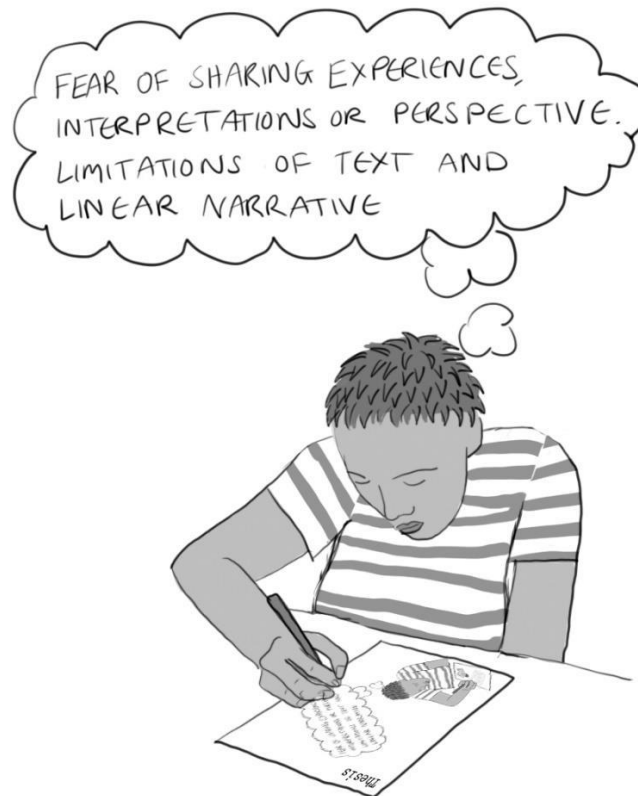
Practitioners can counteract the devaluing of survivor knowledge by promoting a culture in which specific and subjective knowledge based on lived experience is valued. This can be done by inviting, valuing and acting on these types of knowledge in their practice.

When evaluating testimony and creating opportunities for survivors to share testimony, professionals can be mindful of the ways in which survivors position means that they might benefit from using hermeneutic resources created by and for survivors. Practitioners can

also recognise the value in survivors developing interpretive resources outside the mental health system, and not assume that all knowledge is produced within mental health systems. Furthermore, we can endeavor to make ourselves aware of survivor developed interpretive resources and how they might add to our understanding. We can also hold prevailing clinical tools lightly in recognition that they are only tools and that they may not be the only or best way to understand (and then respond to) survivors' experiences.

Concluding personal reflections

I have experienced the whole process of conducting this research, deciding on and using the methods I used and writing (and drawing) the thesis as an embodiment of the issues that the research focuses on. That is - I have felt as though I have been inside the problems and the problems have been inside me. Having been in situations in which it wasn't safe to share testimony and having been told repeatedly that my perspectives do not count, and that I was lacking in epistemic capacity/insight it has been very difficult to allow myself to do anything other than gather and present information with no explicit interpretation. I suspect some lack of epistemic confidence and sense of trepidation is not uncommon amongst PhD students. However, for survivors like me, whose profound experiences of silencing and invalidation are what drove us mad in the first place and whom have had these compounded in the mental health system – these issues are even more acute. Despite this, I hope I have laid out my findings, interpretations and recommendations clearly.



Despite my decision not to do a practice-based PhD because I didn't believe creative practice would be valued, I have found myself returning over and over again to creative practice and the ways in which it can enable sensemaking and communication. In addition to finding arts-based research and visual articulation suitable and useful for understanding my research, I also found using them beneficial for my epistemic confidence. This is because it involved using interpretive and communicative tools which suit how I think. As a survivor I've found my lack of epistemic confidence to be debilitating at times, so being able to support my epistemic confidence in this way has made a huge difference to me and my ability to develop and share my understandings. In turn, my epistemic confidence has been a useful epistemic resource, in that it helped me understand my participants use of zines. Reflecting on this also helped me to understand my participants' use of zines.... Although I recognise that the interpretive and communicative tools that work best for me, and other survivors, will not suit everyone's way of thinking, I hope I have demonstrated some of the benefits of survivors creative practice through my research process and the way in which I have created the thesis.

I have learned much from participants about the different ways zine making can be utilised and

how this creative practice can be beneficial to survivors. I am grateful to have had the opportunity to learn this, as well as learning from participants about the benefits of alternative epistemic landscapes; specifically, the benefits of safe(r) environments in which we can share our testimony without shame, environments in which our subjective knowledge is valued, and where we might collaboratively reflect on experiences and define concerns. It has been hugely refreshing to come to an understanding about this, and about the advantages of engaging with alternative epistemic environments. I hope the light of understanding that survivors gather and develop in these environments via zines can be carried into more corners of the MH system and wider society.

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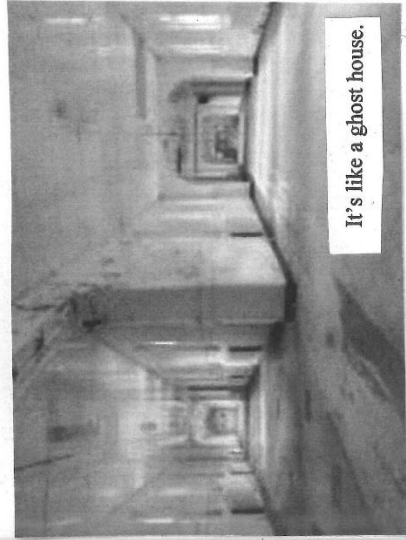
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Appendix 1 'Asylum' at Highroyds zine

'Asylum' at Highroyds zine is on following page. For best reading experience, cut and fold as a mini-zine before reading. For info on how to do this see:

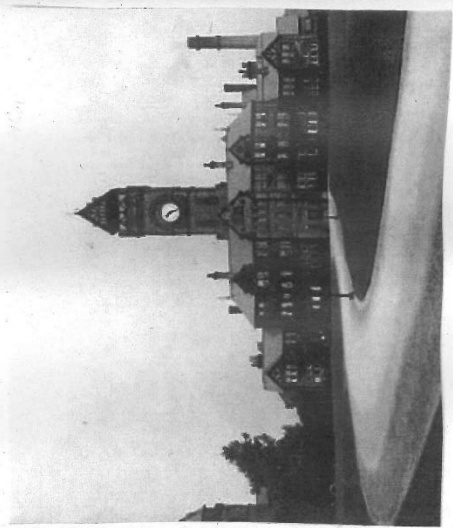
<https://www.youtube.com/watch?v=keX3nBEcw2Y>



It's like a ghost house.

Empty

This is where I arrive.

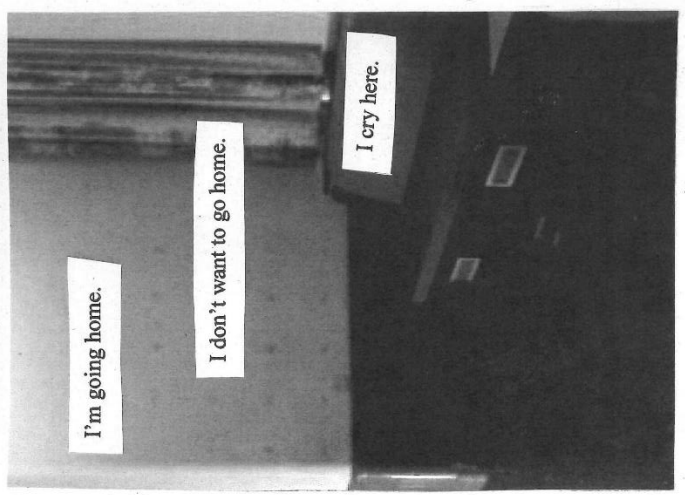


The phrase 'round the bend' originates from the way that asylums were always kept hidden round a bend in the road.

I'm not going home today



'Asylum' at Highroyds



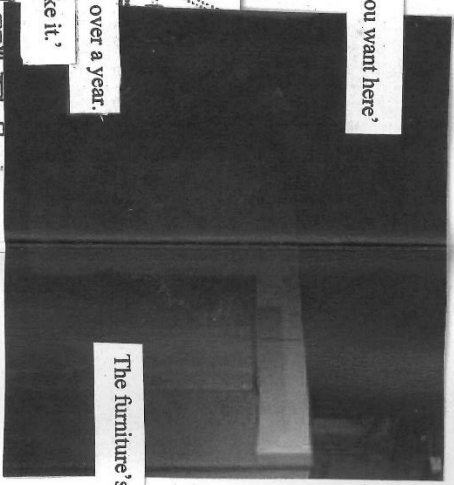
I cry here.

I don't want to go home.

I'm going home.

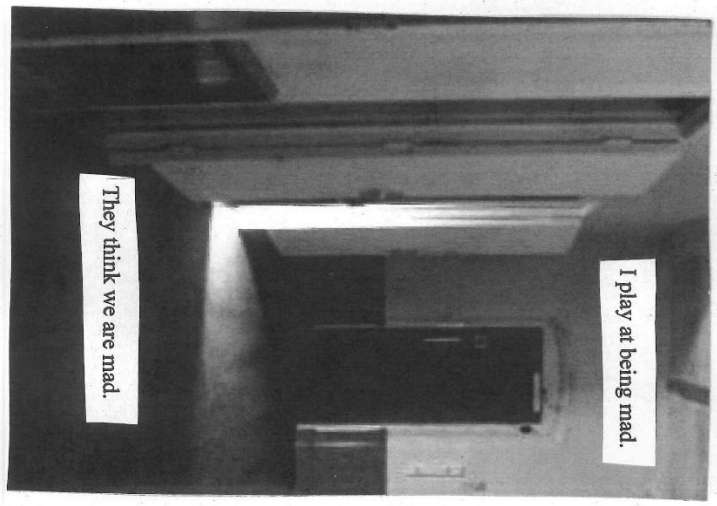
'You can be who you want here'

'I've been here for over a year.
'My voices don't like it.'



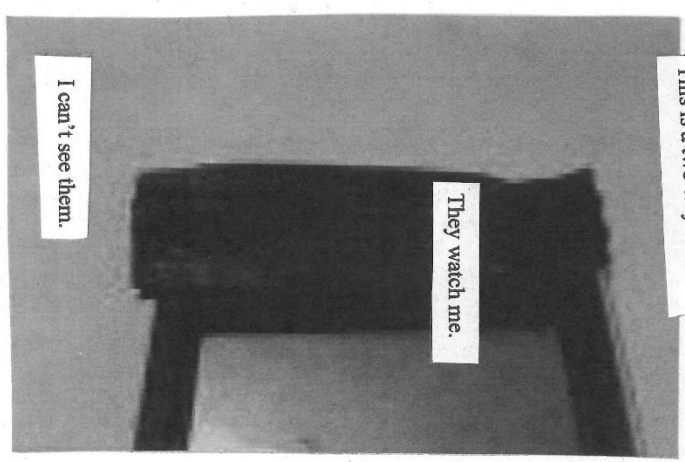
The furniture's gone, it must be movable.

They are holding me down. I'm scared.



I play at being mad.

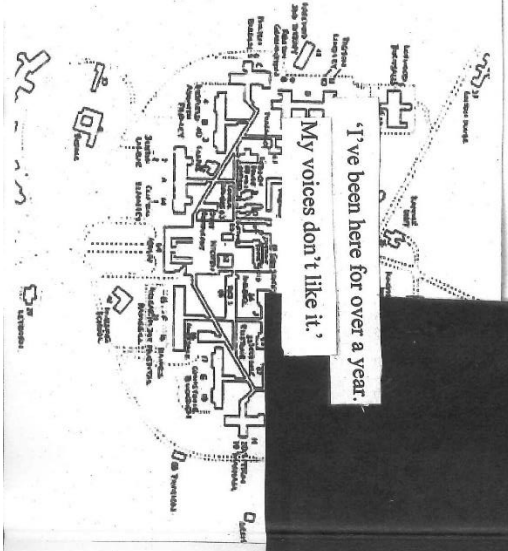
They think we are mad.



This is a two way mirror.

They watch me.

I can't see them.



Appendix 2 Survivors Voices zine

Survivors Voices zine is on following page. For best reading experience, cut and fold as a mini-zine before reading. For info on how to do this see:

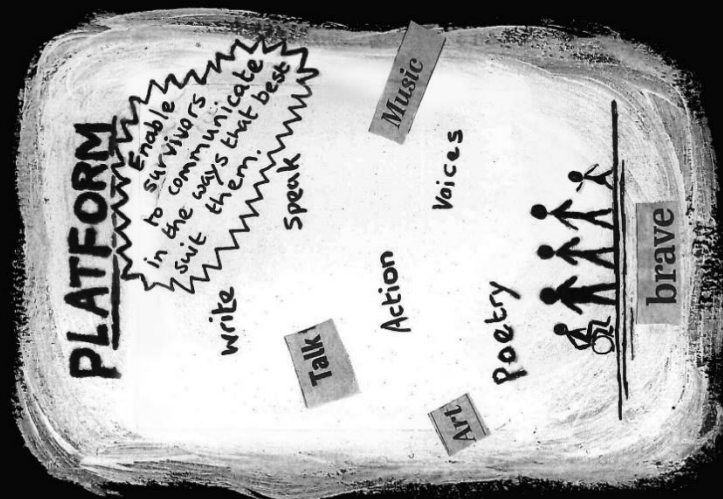
<https://www.youtube.com/watch?v=keX3nBEcw2Y>

and pictures

WORDS

Survivors
voices

- I want to be heard.
- I want to be seen.
- I want to make a difference.



THREATS

FEAR

shame

JUDGEMENT

Why make myself vulnerable by speaking out?

Looking forward ...

- Listen and hear.
- Acknowledge what is shared.
- Be open to learning.
- Enable survivors to set agenda.
- Actions directed by survivors.
- Let survivors know impact their voices made.

If we are not enabling survivors we are silencing them

It's important that survivors experiences feed into narratives about sexual violence. The legal system, media, and wider society can learn a lot from survivors.

MEDIA



Spain goalkeeper David de Gea denies forced sex party claim - BBC ... Spain goalkeeper David de Gea denounces as "lies" a claim he organised a sex party with prostitutes for teammates. bbc.co.uk

This is not justice

This needs to change

Appendix 3 Ethics Approval



University of Central Lancashire
Preston PR1 2HE
01772 201201
uclan.ac.uk

01 February 2021

Helen Spandler / Tamsin Walker
School of Social Work, Care and Community
University of Central Lancashire

Dear Helen / Tamsin

Re: BAHSS Ethics Review Panel Application
Unique Reference Number: BAHSS2 0158 Stage 1

The BAHSS Ethics Review Panel has granted approval of your proposal application 'Zine and heard'. Approval is granted up to the end of project date. *

It is your responsibility to ensure that

- the project is carried out in line with the information provided in the forms you have submitted
- you regularly re-consider the ethical issues that may be raised in generating and analysing your data
- any proposed amendments/changes to the project are raised with, and approved by, the Ethics Review Panel
- you notify EthicsInfo@uclan.ac.uk if the end date changes or the project does not start
- serious adverse events that occur from the project are reported to the Ethics Review Panel
- a closure report is submitted to complete the ethics governance procedures (existing paperwork can be used for this purpose e.g. funder's end of grant report; abstract for student award or NRES final report. If none of these are available, use the e-Ethics Closure Report pro forma).

Yours sincerely

Daniel Bürkle
Deputy Vice-Chair
BAHSS Ethics Review Panel

* for research degree students this will be the final lapse date

NB - Ethical approval is contingent on any health and safety checklists having been completed and necessary approvals gained as a result.

13th August 2021

Helen Spandler / Tamsin Walker
School of Social Work, Care and Community
University of Central Lancashire

Dear Helen / Tamsin

Re: BAHSS Ethics Committee Application

Unique Reference Number: BAHSS2 0158 Amendment_12Aug21 [F2F]

The BAHSS2 Ethics Panel has approved your proposed amendment to your application
'Zine and heard' for face-to-face participant interactions.

Yours sincerely



Daniel Bürkle
Deputy Vice Chair
BAHSS2 Ethics Panel

Appendix 4 Zinester interview prompts

Your creative/zine making process

To begin with could you tell me about how you make zines, what process you use?

The contents/narratives of the zines you make

Could you tell me what your zines are about, what are the contents of your zines?

Your reasons/motivation for making zines

I'm interested in what motivates you to make zines....

The relationship between the zines you create and the process(es) you use to create them

Is there a relationship between the zines you create and the process you use to create them?

Could you say a bit more about that?

If you use different processes do think your process comes from what you want to communicate or the other way round?

I'm interested in whether different processes lead to different zine content?

If/where/how you share/distribute your zines

Do you share or distribute the zines you make? Could you tell me a bit about that?

Your reasons/motivation for sharing your zines

Could you tell me what motivates you to share your zines?

Do you share all of them? If not which do you share and which don't you share?

Who you share zines with/who you would like to read your zines?

Who would you like to read your zines? Do you know who does read your zines?

What you share through zines

We've talked about process and content/topics of your zines. Could you say a bit more about what you share in your zines, in the sense of do you share thoughts, feelings, memories, stories, information or something else?

Responses you have had to zines you have shared

Do you ever hear back from people who have read your zines?

What responses have you had from people?

Your thoughts and experiences of zines as a medium for raising awareness

Could you tell me your thoughts and experiences of zines as a medium for raising awareness

Experiences of influence through sharing zines

Are you aware of your zines having influence? Can you think of any examples of this? Have you been influenced by other people's zines?

The ways in which creating and sharing zines affects your connections with others or sense of community

Does making/sharing zines affect your connections with others or your sense of community?

Political action(s) linked to or arising from creating and/or sharing zines

Can you give any examples of political action(s) linked to or arising from creating and/or sharing zines?

Appendix 5 Zine qualities zine

The zine qualities zine starts on following page. For best reading experience, print back-to-back then assemble pages and fold in half before reading.

Thank you to:

Reflective zines

Kirsty

Rin

~~Li~~

Sophie

Luna Tic

Annie Pocalypse

Dolly

Kira

~~Li~~ Lisa

SELF-PUBLISHED
NOT THROWAWAY OR INSTANT
NON-MAINSTREAM
EDITORIAL CONTROL
(MAD)
ZINE
IMPERFECT
(SURVIVOR) ZINE COMMUNITY
QUALITIES
EMBODIED
FLEXIBLE
CREATED FROM MENTAL HEALTH SERVICES
NOT FOR (COMMERCIAL) AUDIENCE
AWAY
MIRRORS MENTAL HEALTH / THINKING PROCESS
more than just words
and other non-mad-friendly places
SMALL SCALE

Editorial control and self publishing

p.1

I can do it my way, control over contents, less space between creators and readers, anyone can make a zine, reattributing blame, shame and responsibility, public record, trust in unmanufactured, financial limits.

Created away from mental health services (and other places that are not mad friendly)

p.9

Mental health services, academia, workplaces, mainstream mental health campaigns, rejection of dominant (over) simplistic narratives, creating what is missing

Flexibility of the creative process (and structure)

p.13

Variety of creative processes and structures, alternative resources, more than just words, connection with self and others.

Mirrors mental health/thinking process (Madness & mess)

p.17

Process and structure reflect mental health/thought process, Accessible/mad friendly, can be done at home alone

Flexibility of structure (and process)

p.20

Complex multi-layered narratives about things that are unresolved, doesn't have to be emplotted, structure can involve flaps and bits that fold out, can communicate things not possible to communicate on social media.

Small scale

p.22

Being able to distribute in a variety of ways enabled zinesters to **tailor the distribution to what they wanted to achieve** and who they wanted to read their zines. Sometimes this meant targeting individuals, organisations or events, sometimes it meant tabling at zine fairs, sending to friends or sharing on social media. These were seen as strengths for **beginning conversations**, enabling survivor led narratives to **go into services (by the back door)**, and **making links** with other survivors or potential allies.

Not being throwaway/instant mean that they was a certain **commitment** from zinesters and led to **trust** in zines. As one zinester said "Russian bots don't make zines".

Zinesters described **not creating for an audience** as a strength as it enabled to narrate **what they chose in the way they chose**. It also enabled them to draw on **personal resources** they might not have drawn on otherwise.

For some zinesters it was important the process/zine were **embodied**. This was seen as a strength in terms of **contact** between zinester and reader (especially during lockdown), it was also described as a strength in that **zines weren't restricted to zines/bookshops**. The physical nature of zines led to some physical restrictions on what can be created but this was described as a strength not a limitation, it was seen as helping **contain** the narrative.

Being **DIY/imperfect** was seen as a strength because it enabled people to create zines and to use techniques they didn't feel they were "good" at.

Being **non-mainstream** meant that zinesters could use a different **language/voice**, it was seen as a strength for **critiquing and satirising mainstream narratives** although some people also wished the **people with power to make changes** would read their zines.

Strengths and limitations

Editorial control and **self-publishing** are strengths in that they enable zinesters to have **control** over what they communicate and how they do this. They are strengths in that they enable people to create and share narratives that **otherwise would not be shared**. They enable zinesters to make public declarations about blame, shame and responsibility and to create **their own public record**. Some people place value on them for being **unmanufactured**. **Financial constraints** effect how many zines are made and will prevent some people from being able to make and share zines.

Being **created away from mental health services** and academia enables zinesters to communicate things not welcome in those spaces, this includes being able to **reject simplistic narratives** or **happy ever after stories**. It enables zinesters to create and communicate narratives which are **not about the dominant groups**.

Flexibility of process and structure enable the creation of **complex multi-layered (sometimes conflicting and unplotted) intersectional narratives** which **draw on alternative (usually personal/private) resources**. It makes it possible to communicate things **not possible to communicate on social media**. The use of images with text may be strength for **connection to the narrative** and **communicating emotions** and thoughts that would be difficult to communicate otherwise. The flexibility of the process mean it is **mad friendly**, it is **accessible**, and it enables the creation of narratives which mirror mental health and/or thinking process.

Whilst being **small scale** may be a limitation for raising awareness on a large scale it was seen as a strength in zines as zinesters see zines as doing something different, something more **personal**, rooted in **community** and feelings of **trust**.

Trust in the **zine community** enabled zinester to communicate things they didn't feel would be welcomed elsewhere. They felt safer to communicate as it would be **welcomed in the zine community** and people outside the community **wouldn't be able to read/understand zines**. They also said they would be more like to place trust in and **act on zine narratives** because of this trust. People who felt marginalised elsewhere **didn't feel marginalised in the zine community** however concerns were raised about how **white** the zine community is.

Association with particular community/communities p.24

Linked communities, insular (shared culture), Safety/welcome, increased trust in zines, limits who reads zines, its not all about numbers, communication between individuals not organisations/institutions, not marginalised here, who reads zines, concerns its very white

Flexible distribution (swopping, dropping online & in person) p.34

Can change according to need/aims, doesn't need to be commercial, targeted audiences, invitation/information, swopping and contact

Not throwaway/instant p.39

Take investment, cannot be unprinted/called back

Don't have to create for a (commercial) audience p.40

Can create for self, not elicited by others, don't have to be generalisable, more variety possible, can be specific and intersectional, tailored to readers, don't have to write on a particular topic or in a particular way, don't have to be palatable, can be read by people who cannot afford to buy

Embodied p.46

Personal contact and connection, can go to different places (not restricted to screen or book shop, physical limitations

DIY/Imperfect p.49

Can do things I'm not confident at, takes pressure off, freedom to be myself

Non-mainstream p.51

Different language/voice/culture, critique satire and humour, who will read zines?

ZINE QUALITIES

Zinesters highlighted particular zine qualities:

Editorial control and self-publishing

Zinesters spoke about editorial control which came from zines being self-published. They saw this as a strength as it made the process accessible and enabled them to decide on what to narrate and how to narrate. This often meant zines were about topics they didn't see covered anywhere else or things they couldn't communicate anywhere else. They suggested that because zines are self-published anyone can make a zine. One zinester spoke about having control over what is shared enabling it to be a process of reattributing blame, shame and responsibility.

I can do it my way

I started making zines after I gave up that publishing deal because, uh, it was a way for me to, I guess, share my ideas and experiences, that was accessible. It made me feel happy. It was just really liberating I guess, not to have those kind of boundaries and rules, to be able to do things on my own terms.

I still come back to making zines. Because there is that like control over them because you're not like facing an editorial hand. And so you're making decisions.

there's a lot of control you know. I hope I would change throughout my life. For right now. I'm very much like, oh, this is very controlled. You know this is this is just the kind of scale I want right now.

(1)

Who will read zines?

Not being mainstream may be a limitation to getting people outside the zine community to read zines, value them and act on them

I do wonder how many people will be motivated to read zines. Like for example, thinking about, you know, for example like some older members of my family, would they pick up a zine, that looks like a zine that I had made and read it?

Who I would like to read my zines. I'd love it to be read by the people its criticising as well, but I know that won't happen. Unless I create a maze, and put oversized, the pages of the zines on the walls and shove people like Boris Johnson in. And they have to be tested on their way out to see if they've read it or not. That's the only way I can see that happening.

They're quite contained to their own community so. Mean, ironically, you know the thing that makes, maybe people dismiss zines is the same thing that would make them dismiss my specific voices. were like, oh, we don't wanna hear about this kinda. You know, people write zines, they're not. They're not real writers. They're not really know that too political

(54)

And I've been in and out of the system. I'm out if it
thankfully at the moment. And I've done. I've done writing
a letter of complaint. I've done the committee thing. I've
done the media thing. I've done, I've actually been to the
house of lords to talk to the lords and ladies. I've done
standing outside the Maudsley with a placard. The most
effective thing by far is finding a way to laugh at
oppressive systems because they don't know how to
respond back.

CRITIQUE
SATIRE
HUMOUR

53

Control over contents

Editorial control (combined with being self published)
mean it is possible to create and share narratives that
haven't been asked for/have been excluded from other
places

Why should I keep that anger and pain just in our room?
Why should I not let the world know about that kind of
thing?

In a lot of my life I had always hidden the fact that I was
dealing with mental illness. And so this is definitely a way
to, I don't know, be more genuine to myself and be more
open about what I experience.

I think it's that thing about like things that are unspoken.
I think even within like supposedly alternative
communities we can still have things that are unspoken
or that people don't know how to say or how to
reconcile.

I think there's a lot of stuff that I've read in zines where
I've thought I've literally never read a fucking thing that's
talked about this before, like not a thing. And I think that
does motivate me. Like I get reviews from people who
are like 'I thought I was the only person who felt like
this'.

Even with my mom, there are things that I wouldn't
necessarily feel comfortable, just straight up telling her
but when she reads my zines, it almost allows her to start
the conversation,

2

I think it's that thing about like things that are unspoken.

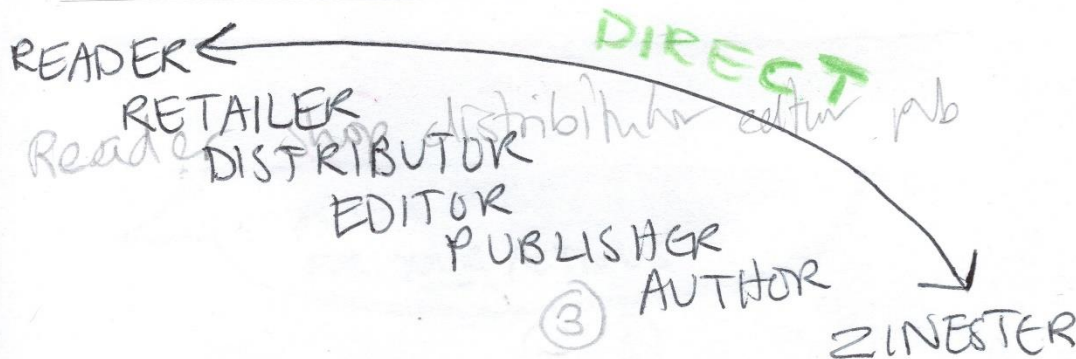
Topics I felt like weren't being discussed so much in other places. Or maybe topics that I found other people struggle to understand. Or topics other people didn't want to hear about.

Less space between creators and readers

Strength in terms of inviting a response (partly connected with zines distribution)

even when it's just sort of me on my own putting my experiences and stuff out there. like I said, I find that resonates with other people and I tend to then get responses from people of like: this this totally rings true for me, or I've had a really similar experience. Or like yes, I have exactly that feeling as well. So it's a different kind of collaborative reflection, but that definitely happens as well.

a lot of times I've found the zine creator and I have written to them. And I've said that I love it so much. And I think normally they have written back, for sure.



And there's something about the voice of zines that might feel a bit, it's just too much. I could see, you know it's too much to hear at once 'cause there's a lot. It's a very confident voice, which is, like, you know, this. This is my way of doing things, this is my story that I'm telling and I don't have feel like I have to feel bad for it and it's really good.

But some people I could see that defence reaction was like 'no', you know, 'you don't have', 'I don't want to hear your voice'.

Critique

Being able to draw on mainstream (and psy) words/formats/images and flip them can be really powerful tool for critique

Yeah. I think that that like reclaiming of the language sometimes can be really powerful, like just taking that format in itself and flipping it on his head. Turning the power dynamic on its head is like is really recognisable for some people, like just that format. But then it kind of gets a double take when people realize it's satire. Yeah?

Can use satire/humour which may be more difficult to do in relation to mental health if done in different settings e.g. outside zine/survivor community or inside places that are not mad friendly but it can be useful for critiquing mainstream/power.

Non-mainstream

Zines aren't (shouldn't) be used to recreate mainstream culture and shared (dominant) wider cultural narratives

I mean it doesn't suit everyone. You don't see the womens institute making zines. (laughs) Or your local church making zines. It is people who are on the outskirts of society trying to create their own culture in society.

Being nonmainstream means being able to critique the mainstream

They are always in some way always political.

It's a rection to something that's happening in the world, so it won't be about the flares of 1974. It's a reaction to something something that's happening.

Different language/voice/culture

Non mainstream means not having to use mainstream language/voice, this may be linked to zine/survivor culture/community

When I first started to read zines I was a little put off because they were quite, They feel they really seem to belong to a different cultural frame of reference and I was a bit like, oh these people are angry.

I read a lot, maybe political zines, not so much perzines but um, You know, I think I have heard that from a

couple people, that feedback that zines are too intense and angry and such.

Having editorial control may mean its possible to communicate things that would otherwise go unspoken and in turn this may be a strength in terms of enabling people to be more open

It makes me think about what personal stories all the people I meet have, that I don't know anything about. Zines have encouraged me to be open and vulnerable with others, and I've found out more about the people around me, and their own difficulties and struggles and inner worlds and thoughts.

Anyone can make a zine

Self publishing may be a strength in that it enables some people to share their narratives publicly who might not otherwise be able to

Anyone can write them. Like I said, you don't need to be asking permission so you can support anyone to share their experience with that medium.

What I like most about zines is that. You don't have to be a professor or a teacher or anything. You don't have to have any like social status to be able to have your voice heard, yeah. And I think that's important.

Reattributing blame, shame and responsibility

Having editorial control meant zinesters could choose to make a public declaration about where the responsibility lies for the issues they had raised and invite readers to witness and/or act on this. One zinester described this as an act of anti-shaming as to choose to share it publicly was to declare an absence of shame. This was also apparent in my reflections on my process of naming and sharing Not My Shame, which was essentially the action of making public things I had experienced lots of feelings of shame about.

What the main thing of my zines are is this thing around shame, that I see in a lot of people's lives and it used to be in my life. This thing, you should be ashamed of all sorts of things. For example, let's use the first zine as an example; so, you should be ashamed to be an older person. You should be ashamed to be a person in physical pain. In some worlds you should be ashamed to be a gay woman. It's all this. So, if I just bring it and just shove it in people's faces: And say "This is my life. It's really funny. I don't have any shame about it. Then whoever thinks they have that power over me, they don't have it.

I AM NOT
RESPONSIBLE
FOR YOUR ACTIONS

(5)

But also my own history, that I was trying really hard to be a writer. Went to classes and all that and. So I was trying really hard to fit in specifically. Maybe, I don't really know whether arts, I have. I'm terrible, you know, I'm really bad at drawing, but I really enjoy it

Takes pressure off and makes people feel they can make them

With zines, I don't feel that pressure to be perfect. I just have to show up as myself and express myself -- the rest will follow.

I think I have been influenced a lot by zines in general -- I loved the idea that it didn't matter whether I "could write" or "could draw", I could just write and draw what I want, print it, and people can buy it if they like it

Freedom to be myself

There is a feeling of freedom that I don't have with any other kind of media that I produce. There is a feeling of wildness, a feeling that anything goes, a feeling that this is a safe space but also a space that I can really and truly be my whole authentic self. In this way, I feel comfortable showing all of the messy parts of me that I wouldn't otherwise share.

(50)

DIY/imperfect

Being DIY/imperfect is seen as a strength as it meant some zinesters felt they could make zines and didn't feel under pressure to try and be perfect. It gave the freedom not to conform and meant that zinesters felt able to use techniques they didn't feel confident with or "good" at and could just be themselves.

I don't know. I would feel like I had to make it better if I wanted to give it to more people. And then I would think Oh I should make the writing bigger so its clearer. Or I should correct this so that it's not so messy here. Or ...

I'd feel like I had to polish it a bit more.

We're so bombarded all the time just as people with messages that everything's gotta be perfect. We've gotta be perfect, the things that we're doing have gotta be perfect. And I think there's something very freeing and liberating about, I'm just going to make this thing, and I'm going to put it out there. And it felt like a much more sympathetic way of working with my specific experiences of like being mentally ill.

One zinester spoke about using art in her zines even though she didn't feel she was good at art, it wasn't about trying to achieve something or be good at something it was about enjoying the process and communicating

so I personally feel that whenever I'm open and honest about my sexuality or my trauma or my mental health, that it is in a way, a political action. At least where I'm living because, Um, those things are not accepted fully here.

My dad is Indian, my mum is Scots Irish and so I experienced racism growing up. For most of that time that racism was, I took it, I internalised it so I thought I was the alien, the dirty person, the wrong person. Its only when I understood, actually I don't own the shame, it doesn't belong to me, that my mental health got better.

"It's no accident people in oppressive systems want people to take on that shame and stuff because it's so powerful. So, it's a tiny little step in saying, 'no have your shame back'".

We are missing the point if we see survivors' narratives as only being about telling people what happened, it can also be a declaration of an absence of shame and a request for witnessing and acknowledgement, which by implication calls for people to reconsider where responsibility lies and what should/could be done differently.

Self-published

Public record

I understand history and I understand archives and stuff like that and I don't want people to look back, say during the last couple of years and say 'nobody said this about this during covid time'.

...

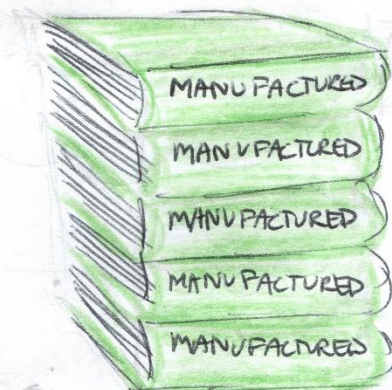
Even if we don't change history, we just changed how people view it.

One zinester said they had more trust in zines because they are self-published and so less manufactured.

If you wanted to write an article in a magazine or a book, it would need to be published by someone else and therefore it would have to meet a lot of criteria. Someone else would need to decide it was well written, interesting to lots of other people, and commercially viable.



V S



⑦

Physical limitations

Zines can be as small as an 8 page minizine or as large as a small book. There is a form/structure, there are physical limitations and they cannot go on for ever.

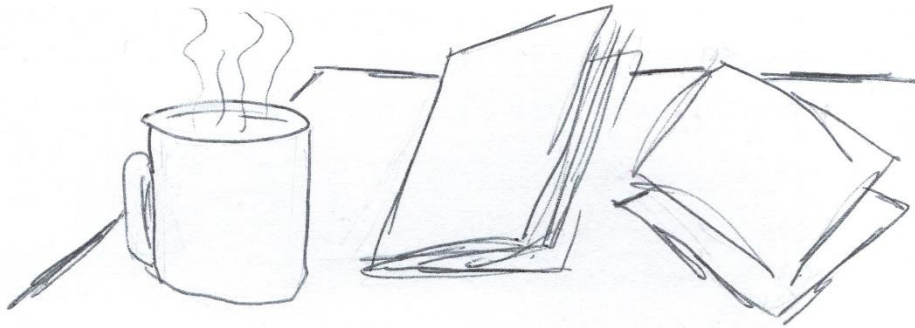
So I think zines. Because they were quite small, format is inside make so kind of by its nature. You tried to boil things down into the most readable or accessible, facts or points.

And I never send a letter with my zines because I feel like, I would always find something to add or to put in that feels a bit personal. You know I don't want to put a letter. Maybe it's me because I feel like the Zine is the person I'm sending. You don't need to know about me, you know the zine is what I'm sending you.

That's definitely mental health thing, like you're keeping it contained. Uh, if I try to write a letter, I will write it again and again and again, get really overwhelmed. Maybe like I want, you know, I just I just can't, it just overflows.

I don't know what to do, so that the Zine is a good kind of format that really helps me. 'cause I've created something and it's an object then, it's got a lot of myself into it. But it really kinda helps you know. If you're quite introverted and if you're quite guarded and, you know if reality is not given. You know there's that.

④⑧



Zines can go to different places (e.g. not restricted to screen or bookshop)

Zines could go places they might not otherwise go e.g. mental health services.

I feel that you can get it out further with the zine. spread the information further than you might be able to do with a blog or whatever. And. But there are also things, in

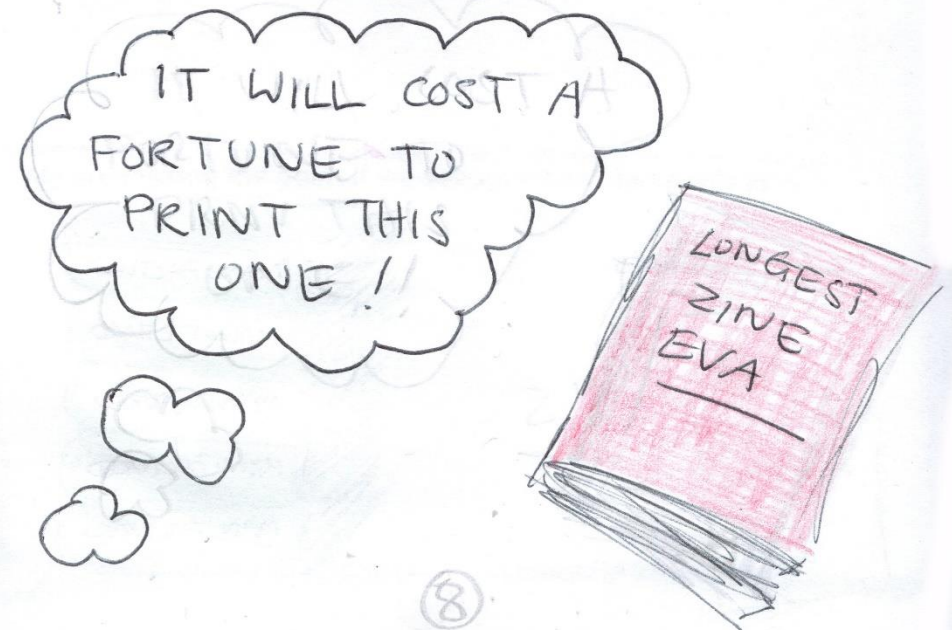
terms of like, once you've then got it, you can continue to distribute that, over and over and over again. If that makes sense, like very quickly.

I think when I was, especially when I was younger, I think if you walk into a bookshop, or in to community space and you see a Zine. And you can kind of open there, read it, and it's quite a personal experience and it's quite nice and you can walk away thinking what you want of it. And that could be, you know it's a relationship.

However as Reynolds (2019) suggests the being able to self-publish may not be possible for everyone. Some zinesters said that printing costs limited how long their zines were, how many copies they printed or whether they kept in electronic form.

The reason why I had the PDF of this zine is 'cause it was so long and printing it was quite a lot of effort because of the kind of subscription I have. You know, I pay for a certain amount of pages every month and that's kind of a good way to not overspend, you know. And that's why I made it a PDF

The Zine I made that about my breakup, that was quite a lot of pages and quite a lot of ink. So for example, that one I printed maybe like 2 copies, but otherwise I just put it on download on my Tumblr.



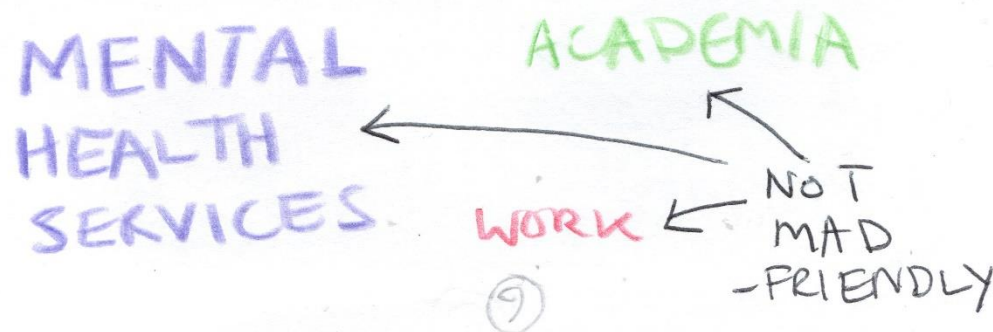
Created away from mental health services and other places that are not mad friendly

They could be a response to experiences of services that was created and shared away from services. This meant that zines can express emotions and ideas not welcomed in those places and communicate in a voice/tone not welcomed in those places.

So That what the 'Psych Trauma' zine was, you know I was just back from my appointment and I started to draw, and to kind of like, I was just really triggered and stuff. And then I was like This is looking quite cool this could work as a zine. So that's really what my process is.

I'd had like a really shitty meeting with a psychiatrist, and I was fuming like pure raging and I was just like right then I'm just going to fucking make a zine.

I don't have many opportunities to be angry to peoples face. Um. I mean, at the time that I wrote Shitfullness I was displaying anger at like the mental health team and stuff, but I also had to limit it, because as we know if you're seen as angry, you're not worth helping and all that kind of crap.



Embodied

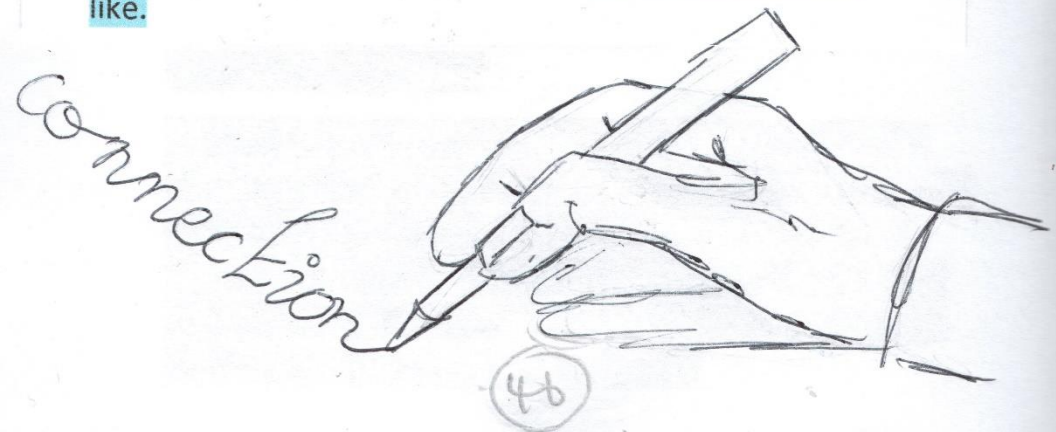
Zine making can be an embodied process which results in a physical product. The embodied process may be strength in that people may feel more connected with what they create or what they read. It may be a strength because it means zines aren't restricted to screens. The physical limitations may even be a strength as they can make it feel contained.

It feels more like personal contact and connection

The hand making them in the handwriting them is a kind of deliberate act to try and connect with people. And. Which, yeah, again, like. I hope reflected in the zine that I did, it was like community.

I think especially during Corona, there's something really special about touching something that I know something else someone else has touched. and yeah like when I do the.

I do mail out a lot as well and then. That it's like there's something that is. Special about like having something that someone else is also had contact with that I really like.



Don't have to be palatable

I think it does bring a secretive topic into a public place

About zine about bulimia:

But I think there is value in it just being there, on my table. Especially because it specifically says bulimia, which I think has extra layers of shame around it, because it can be associated with lack of control and vomiting – both of which society see as unpleasant.

Zines can be read by people who cannot buy them

for my mental health zines if somebody reaches out and like doesn't, like wants them or says like I'm going to buy these when funds are available or something like that, I usually will just send them copies because it's all about like access.

Being created away from wider society and workplaces means zines can be used to communicate things not welcomed in those places.

"Shitfulness is very much me taking the piss out of mindfulness, but when people talk to me about mindfulness to my face I always have to say, you know, like "mmm, what a good idea", "Yeah, I can try that". Or, you know, at work at some point I was delivering training and we had to do a little bit on mindfulness and I can't display what I think ... I understand the principle of mindfulness, but overall it is a bullshit thing that has been created to dismiss people. I can't say that."



It also means that zines didn't have to conform to a specific structure with a single plot that conforms to organisational expectations and is easy for audiences to digest.

Like in like anti stigma campaigns and like mental health like more like mainstream campaign in that was about narrative that was about being able to tell a good story about your experience and make that feel like digestible.

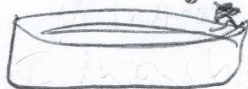
Because they are created away from academia there isn't the pressure to use academic language/ways of communicating.

"I think the language of zines I'm much more comfortable with"... "I've always struggled with education and academia"... "I've had some education but I feel uncomfortable like trying to fit into that world and trying to learn all the language that I need to use to sort of be taken seriously. And. With zines I can just use my own voice."

You need to use more academic language

Try re-structuring it adding an intro. syn p. and conclusion

This is a personal honest emotional rant based on experience and thought.



I thought about it

in the bath.

It follows my thinking. I was angry remembering what happened.

Taylor to readers

Can tailor to individual readers, like a letter or a gift which was seen as better for connection and care.

But I always try to put a bit of intention. and see if someone buys my zine on Etsy, I might click on their profile and see what's in their wish list, and according to if it's appropriate I put something there, in there art that's relevant to what they like or whatever. My zines, have handmade elements to them and to me the process is quite connected to that feeling of wanting to connect to someone

JUST FOR YOU 😊

Less pressure to write on a particular topic or in a particular way

Commerciality is a barrier – if someone's ideas and experiences aren't commercial, they won't be made into films or TV programs or books. Even stories about mental illness or health or sexuality or race, they're told through a certain lens, in a certain way, and they often conform to certain stereotypes.

they have more value in giving people access to a rich, raw, sometimes very personal account of a person's life – a person who may have lots of differences to them, in gender or race or disability/mental health or nationality or class or wealth. That is something that is hard to find in mainstream media, or social media.

Can be specific and intersectional

There was a zine, like it was meant to be a series called 'that's how it feels for me'. So that series kind of explores different themes about my identity. Like having been diagnosed with autism later in life, being queer, being non monogamous, gender, that sort of thing.

My perzine series Forever Incomplete I describe as being about gay stuff, fandom, mental health and tying to be an adult, which broadly covers the content there. Then

single issue perzines I've made quite a lot of stuff about polyamory, more mental health stuff that sort of thing.

GAY
+
MENTAL
HEALTH
+
POLY

QUEER
+
AUTISM
+
NON-
MONOGA-
-MOUS

43

Rejection of dominant (over)simplistic narratives

And the idea that CBT is going to help is kind of saying you're not thinking about your pain properly. You're letting the pain get better of you, lets teach you not to think that way, in six sessions.

The other things health and medicine doesn't do is see how trauma impacts. We all know, well some of us know, it impacts mental health. It also impacts physical health.

It's mostly, I guess it's first person accounts of things that you know are quite different, you know different from the narratives you get at the moment around mental health in the UK which are very sanitized, it's not creative as such you know, it's quite, you know it has to fit a certain narrative and it's, you really lose a lot in there such rich, you know they're rich experiences.

I want I want it to be quite authentic, even though I take quite strong stance. You know, it's not apolitical, it is quite political, but it's also quite authentic and it doesn't have to be perfect. It doesn't have to be linear with a resolution 'and Now I'm feel better'. You know, this is ridiculous!

Creating what is missing

I also make stuff that I want to see as well. When I got this leaflet off the OT I said to (my partner) "I'm going to google if there's one for lesbian couples who've got arthritis". And there was nothing, absolutely nothing. So it's also like, putting in the world things I want to see.

WHERE ARE THE
NARRATIVES ABOUT
LESBIANS WITH
ARTHRITIS?

Flexibility of the creative process (and structure)

Different structures and processes could be used to create different zines.

You've probably have picked up I don't have a one size fits all process, it's dependant on whatever it is.

I think it's whatever suits the subject matter really. So no it won't always be the same process.

I find the formatting with the digital zines is much cleaner and sharper than that of the handmade zines. Handmade zines have a very wild, overgrown feeling to them which lends itself to certain topics. I think if given the chance, I would do a bit of both, because they both definitely have pros and cons.

If you pick up a copy of Cosmopolitan that's not you is it? That's a version of maybe someone that if you are white cis hetro sexual then maybe there are somethings you can relate to but it's not personal, its not for you and the further away you are from those things the less its you. And I think that's the, there's something very personal about reading people zines because its unfiltered, it not about 'what is this kind of person supposed to be', it's like 'who is this individual'.

More variety possible

I think definitely what I've got from reading zines and zine culture is actually, it not about finding someone who is exactly the same as you, it's about finding lots of different people who are doing lots of different things. And actually realising that there are opportunities and then wha'ts for you is there, but it doesn't have to be the same as everyone else, but just like just a diversity of stories I guess and I think that's a big thing for me.

Don't have to write for the dominant groups, can be specific and intersections instead of pretending to be generalisable

if I wanted to share about my experiences of ablism in the queer community I think zines would be perfect for that because those are two areas that are quite strong subjects in the zine world.

... I think it's really powerful if you want to raise awareness of things around intersectionality actually.

Whilst zines are not (always) made with an audience in mind or elicited by services or anyone.

I'd actually just thought about doing in the moment, just making one original one.

It was only later on that I, people liked it and then I copied them and then that's when I took them to some zine fairs.

THIS IS FOR ME:
WHAT I WANT + HOW
I WANT

Don't have to be generalisable.

This may be a strength in that they can be specific instead of being written for dominant groups and then assumed to be applicable to everyone

We don't try and generalize. It's about being like, 'hey, like we're two, like neuro divergent, queer people who went on the cycle tour and these are the things that we found hard and this is what worked for us'. Because like too often you know you'll get like an A to Z of cycle touring and it would just act like everyone is like a thin cis straight white man who's like neurotypical and like not disabled and it's just like 'and this is the generalizable rules about cycle touring'. Actually, like speaking of those specific stuff is like important for us in that context.

(41)

Usually there is something on my mind that I am thinking about a lot – depression, sexuality, houseplants – and to help me think about it I do drawings of what I am thinking about. Then I write up bits and pieces related to what I am thinking about, and when it adds up to enough pages to make a zine

They could be created using a variety of resources including things not initially made to be shared.

One of my favorite zines was about young prospective graduate students. The zine creator had collected notes and photographs on these young possible graduate students from the trash at their university, and organized them so that each person had their most brutal criticisms blazoned across the page.

I would say in 90% of my zines its first a personal journal and then I make it into a zine

More than just words

Can make use of different forms of communication and techniques including drawing painting and collage

It all stemmed from writing, writing came first in that time frame. It was just, sometimes you write a piece, and it needs more than just the words, it needs other things

I like all of my zines to be like that kind of multimedia, a bit of a messy combination

I try to keep a mix of writing and text throughout the zine, so it isn't all pictures together and words together, but otherwise I think the order is pretty random.

(14)

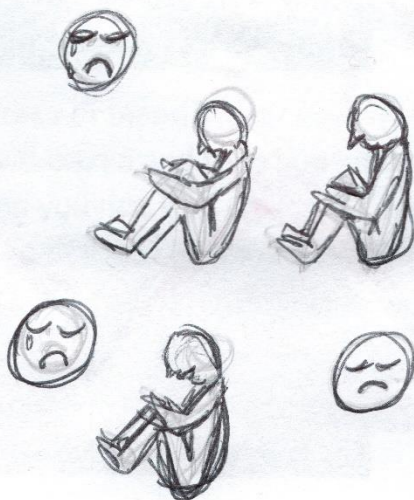
This means it might be more directly connected to zinesters experiencing.

As a depressed teenager, I drew certain pictures again and again and again in all my school books – girls hugging their knees to their chest –...It wasn't until I was older I

thought, oh yeah I was trying to tell people how unhappy I was, and I just didn't have the language.

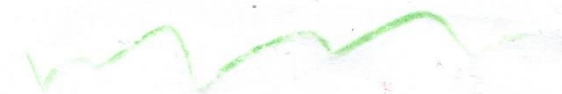
I've always found it really hard to put my feelings into words, I used to have no idea what I was feeling,...

So I draw first, and it helps me move from feelings into words. It's like a middle step between feelings and words.



Also the process of creating can enable people to make sense of and communicate things they would struggle to otherwise

I struggle to put how I feel into words at the best of times, and during the severe depression it was impossible without a lot of forethought. So zines allowed me all the time and space I needed to tease out my thoughts and share them.



Not having to create for a (commercial) audience

Zines may not be made for a commercial audience and they may not be made or an audience at all.

There's very little pressure to cultivate what you are doing to an audience.

They didn't leave the room it was for me, just because I wanted to do them.

Can create for self

When I am writing long-form fiction, or even writing short stories, I try very hard to be polished. Each word has to be chosen with care, and each turn of phrase has to be clever and witty. It is all about how the reader will receive the work. I really try to make it a great experience for them to read. But when I am working on a zine, it is all about me and my process.

Zines are not throw away/instant

It takes time, money and energy to make zines -leads to people valuing them

You know, it really feels like someone's taking the time to write you. You know your friend from school that you really miss over this summer holiday or something, you know. And you know, I really miss that.

I think there's much more than the kind of like current event focus in there, so I, whereas with a blog I think is usually something that is quite timely. I hope that I can continue to distribute my zine like three or five or ten years and for it still to be relevant.

It does remind me of that. That kind of you know, sending someone something that creativity and so that was kind of like the idea behind it I think, is the freedom of the zine format as well as I can do that. I really enjoyed that

One they are printed/out there they can't be unprinted or called back

I think I share this like, moment of my life. Like a little, context-free snippet of my inner life. Looking back on some of my zines now I think - oh gosh I want to re-write that! That's such a weird joke, or that's not something I quite agree with anymore. But I never edit them like that, because then they will lose what they are. Like a tiny time capsule of myself.

(39)

It might also enable a different type of connection with people who read zines

Creative work, (it) is such a huge connector to people. Because the people just, you know, it's not like a business card where you just know what they've done. They understand a bit of you. It's connection on the heart level as well.

*For more about zinesters using different creative processes and structures see Making (un) common sense Zine



(15)

Mirrors mental health/thinking process (MADNESS AND MESS)

The structure and creative process could mirror people's mental health or their thinking process. It was a more accessible process; structure could emerge from the process and zines don't have to be structured around a plot.

It (structure) emerges as I create the zine.

But it always starts from feelings, for me. Yes, it starts from feeling and the feelings really attached to the sense of place you know, and the descriptions of what's going on.

It starts from feeling and then, the kind of ethics, or whatever, the politics kind of graft themselves onto it

You know some people have a thought process that's like A, B, C, D, mine isn't really like that.

It's not a case of being like oh you're alienated from like mainstream media and then you get involved in zine culture and you just kind of, there's not like this expectation that you become this other premade thing.

As I moved from being severely depressed, suicidal and having very little to do – to now where I am actually incredibly happy and content, and very busy – my zine topics and processes have changed.

Swopping (in person) to have more direct contact

Can be a strength in terms of starting conversations, people may be more responsive

I prefer to swap at zines fairs, partly because it's a great atmosphere, but also because I feel like people know what they are getting!

... at a fair people can pick them up and flick through and decide if it's what they want – then just someone buying it feels like a big compliment.

I realised when I started talking more and more openly – both through zines and in person – is that the second you do, other people open up to you too...

... the same thing happens with complete strangers when I sell them my zines.

Inviting people to be allies/Sharing them in this way means you know that person has that knowledge:

Can target people who might benefit or people you would like to know

Sometimes it's because they have like access to another network or a community who might be interested. Uh. Or like they might be a carer for someone who's involved in mad activism or going through difficult time using services or whatever.

So I guess with the targeted drops, I think it's interesting. Like I say, sometimes I think I. Sometimes I drop them to potential allies, who don't know they're allies yet. And, and I think. There's something about that with, Like me, making an action to try and improve my life as well.

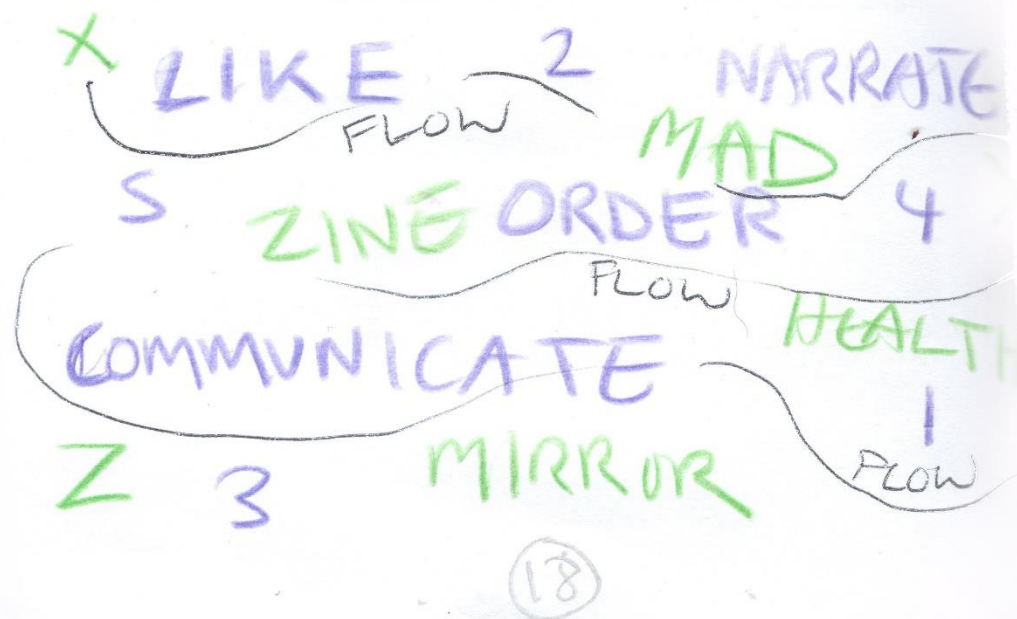
Like when I interact with that person in the future, they have this knowledge. I know that they have that knowledge kind of in their head when we engage in a conversation.

So I think it. I hope that I do that for other people as well. With the other drops and stuff. I think I do it for myself too.

Usually I know the idea of the cover quite early on. But the rest I just put the pages out on the floor and see what makes the better, what has the better flow. So, it doesn't come as like this is page 1, this is page 2 this is page 3. It's like, here's the work, which is the best way to do it. I don't work like that, as you should know by my thought process, my thinking process and my speaking process.

I usually work on different things for my zines at a time because that kind of mirrors like how I would best manage my mental health and. And I guess that you know that's kind of mirrors in what the zine is talking about as well.

We don't have to tell narrative stories to communicate lived experience, we shouldn't have to and these are more complicated and multi-layered and multiple and changing experiences.



Can be done at home and alone

Mad friendly 😊

I became psychotic at, really severely psychotic at 14. And really didn't leave my bedroom until I was about 30. So, I was actually making zines out of um, whatever material was a at hand.

Like a lot of activism, I feel it can be off putting because. When you first. Maybe that is, I think, a lot of people think of things like large crowds and protesting and that kind of stuff. And again, that's not really, It's not really mad friendly

Zines can be tailored according to how zinester are feeling at the time they send it (including crossing bit out or adding them)

Sometimes I would go over my zines when I send them and I will actually go and cross the thing out 'cause I just feel anxious. And yeah, it's this kind of part of the imperfection of the zines as well, you know

HOME AND ALONE
IS MAD FRIENDLY



(19)

Targeted audiences

Being able to to this meant zinesters could target particular people.

But I also do certain amount of like targeted drops with each zine, where I'll pick out people or locations and I'll just give a certain amount away.

And then like I do similar things as craft drops or craftivism, where I drop zines in places where I feel people might frequent, like a mental health service if, pre covid time, like a walk in service or whatever. I might leave some Flyers and zines in places like that.

Contributing to conferences in unelicited and unexpected ways

And we did for Mad Covid last year we gave, I gave a keynote speech with the Royal College of Psychiatrists. And I deliberately placed that poster directly behind me.

Which was hilarious. I thought it was really funny I didn't get any feedback on it. It was like it's a blank wall and then a very obvious truth.



Doesn't need to be commercial

This is a strength in that people who don't have money can access (some) zines for free

I got back into zines a couple years ago as well, because of Etsy. Like Etsy just bloomed full of zines, and it's just mad! And so I really enjoy, even though they charge me for my listings. You know this would be money that I might spend going to an event or whatever. I feel OK about giving them some money. And I have a disclaimer, you know, if someone doesn't want to pay, they can contact me.

the crisis leaflet I sent you which I put online for people to download because I felt like it was important for people to just have that.

Whereas the other one, I haven't thought about making a digital because it, yeah, it's important to me that they're an object, like a physical thing.

Taking it to events and stuff. Like I often pick up zines and things at protests for example, or just out and about in like libraries or coffee shops. Like you could drop them everywhere and spread it, quite fast.

~~£10~~ ~~£5~~ Free to you
35 ☺

Flexibility of structure (and process)

Complex, multi-layered narratives about things that are unresolved

Can create complex and multi layered narratives using different media which are not necessarily emplotted It means it was possible to use different media and create complex multi layered narratives that could be about things that were ongoing or unfinished.

I talk about mental illness with friends and strangers all the time, but I don't describe how it felt in detail – it's a lot more practical than that – side effects of medication, navigating the NHS and private therapists, etc. I needed a space to just open up – and I had read perzines which were more like somebody's diary or blog – and I wanted to do that too.

And it's all a commentary on mental health, whether that be from like a personal or political perspective. Or again usually a complicated, messy mix of the two.

everything comes from a personal experience, but I try to contextualize that with history and different perspectives of experiences.

It is about like wanting to like, demonstrably, like live up to belief in the value and importance of like non narrative descriptions of experiences of like mental health and mental health services

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when I made them I didn't really think of it as a structured process. My zines were less of an intellectual pursuit and more of a mental and emotional dumping ground:

Structure can involve flaps and pockets and bits that fold out:

yeah I really like that and that really reflects my kind of desire to control. But at the same time. Im you know changing my mind all the time so I can never settle on was finished. and. But the main motivation for that was, um that triggered the content warnings. You know, I was very careful. Yeah. With that you know it was that really strong desire to keep it quite safe. But then because you have this freedom with the formats, you might as well.

It also meant you could communicate things it wasn't possible to communicate on social media.

It feels like you can say something different than what you could say on social media. because I use Twitter a lot as maybe you know, and it's you can say a lot more than what you can in think it's 160 characters or 120 characters or however many it is now.

In a zine you can, you can say more in more depth but also you have pictures as well.

Flexible distribution (swopping, dropping, online and in person)

How I share them. I've got a few social media accounts. I find Instagram really good. A lot of my interest for my zines came from Instagram. Also Facebook and Twitter. I also have local links to quite a few arts spaces and political spaces and put stuff there. So that's how I share.

Enabled people to do different things depending on what they wanted to achieve or what worked for them

I have also swapped with people. I'm on a swapping Discord, so that's been really nice. I recently swapped recently for the first time and it's been very nice and I really enjoy swapping now. But Etsy. I'd love to send them more to book shops and things and libraries, to book shops and things and libraries and then I might get

down to that eventually. But because it's lockdown, I'm pretty sure most book shops are closed.

PDFs are really accessible, so you know I had a kind of a sense of urgency with the 'Addiction' zine, 'cause I was alone in my first kind of month of recovery, which I really actually needed, but I also felt like I had so much to say and I didn't want the instant gratification of the internet. So I made this zine and it's very text, text, text, text. So I just wanted to share it, to be like what do you think of this? You know so it's more, I just want a conversation with this one.

Concerns community is very white

It may be that zine culture replicates wider society in that it doesn't centre the narratives of working-class people or people of colour.

I'm thinking about something that I can't particularly like, can't particularly like comment on. But I am interested in

the ways in which zine culture replicates, can replicate dominant culture.

I think there lots of things that are very very freeing and very very different about zine culture.

Its still really fucking white and I'm interested in that and what we do about it.

Are there groups of people who are, well there certainly are, marginalised within this much more egalitarian structure.

Yeah. I would assume the answer to all of those is yes.

This means zines may be limited in their ability to raise awareness of these narratives. This may be a self-perpetuating problem if most people are inspired to create zines after reading zines; if people don't see themselves in zines, they may not feel invited to join the (zine) conversation.

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Small scale

Some zinesters like that zines are small scale, they feel its an important quality.

I can't really imagine reaching that many people with zines. But that suits me, I like that it's quite special and small scale, you know

They say, generally they say 1000 issues is the rule of thumb for a definition of a zine.

It's not something that I think has reached many people it's very very small scale thing for me. I know for a lot of people it's a bigger scale thing but for me it absolutely tiny and it's just something different to the blog. Because I feel like my blog does reach lots of people. But it's not, it doesn't have the same qualities as a zine.



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One zinester pointed to limited audience meaning they could only raise awareness on a small scale but also questioned whether to be on a larger scale they would have to be funded and so less independent more contrived.

I think micro awareness is probably what we're looking at.

The thing is, once anything is mass produced then it's got a motive hasn't it. So, for something, so if you were able to get a piece of writing about mental health say that was big enough that was like, so we're going to make it into a zine but like, is the guardian going to pay for that, who makes that happen, and how does that change the content?

Unless you were entirely self-publishing and self-marketing, I don't see how you could ever not have outside influence on that narrative.



READERS

23

Who reads zines?

Are the people who read zines the people who feel comfortable in the zine community?

I'm seeing the disability world read my zines. I'm seeing a lot of the queer community read my zines.



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Some described zines or zine culture as being queer or referred to their being lots of queer people in the zine community. Consequently, for queer people zines reduced their experiences of Epistemic Injustice, or at least Epistemic Injustice that was related to this aspect of their identity. The same may be true for women, people with disabilities, non-binary people and survivors or people who have experienced difficulties with their mental health.

People, I imagine would read them are like fellow queer, mentally ill, disabled people, um, who want to read about someone else's experience or are like nosy (laughs) about people's life kind of thing.

like when you go to a Zine fest. I mean, there's like a high proportion of like queer people, people who are disabled, mentally ill people, you know people who want to express themselves. Like. And so it's kind of, I kind of see it as yeah an opportunity to, you meet people from that sort of background, you know and like who kind of have human experiences

because. And in like. And those experiences aren't necessarily centred. Those gatherings, right they're not centred, it's not like, 'oh, this is a support group for people who experience the people' that just happens. As in a lot of people who've experienced the same things, but it doesn't have to be centred around it.

The bit of zine culture that I'm in, Per-zines primarily is mostly women, non-binary people, queer people, disabled people

Association with a particular community/communities

I mean where would punk be without zines? Where would riot girl be without zines? Where would queer core be without zines? It's just, it's a really important part of the culture.

Links with slam poetry/spoken word community

I love that the world of zines has this vibe that is a cross between punk and bookish introverts – the world of zines and the world of spoken word poetry are just perfect in that way.

I feel like blogging, spoken word and zine making are like sister arts in a way because I was zine making at the time that would do spoken word and open mic and so some of my poetry goes into my zines and like Vice versa. They are one and the same thing really. and um in spoken word as you may know or you may not know.

A lot of people there they talk about, topics that they haven't had opportunities to talk about in other places because they know that when they talk about these topics they will be accepted in those places.

After finding an audience in the slam poetry community:

I wanted to reach as many people as possible, and I wanted to make sure these people felt known. So I moved some of my slam poetry into zines and created art to go along with it.

Insular (shared culture)

I guess a lot of zines can end up being quite insular, you know they only end up being shared in the community.

I often think like, it wouldn't matter if they ended up in the hands of people who like, didn't share my views or didn't understand, because they wouldn't know what it was about. They wouldn't be able to read it properly so they wouldn't, they just wouldn't get it.

I think that a lot of professionals would benefit from diving into that kind of literature of like first hand accounts, but I don't know if they quite have got the stomach for it. (laughs). ... you know, there's some stuff that's much more, that would basically make them much more defensive.

And I would worry that they wouldn't understand the culture behind it as well. So in a way it's like I want people who read my zines to be people who read zines, to understand what's behind it.

And I do think they do raise awareness but I don't know what I think about. I mean I think their ability to raise

awareness is limited because. but I think its huge, but I think its limited to people who are I guess kind of engaged in the culture.

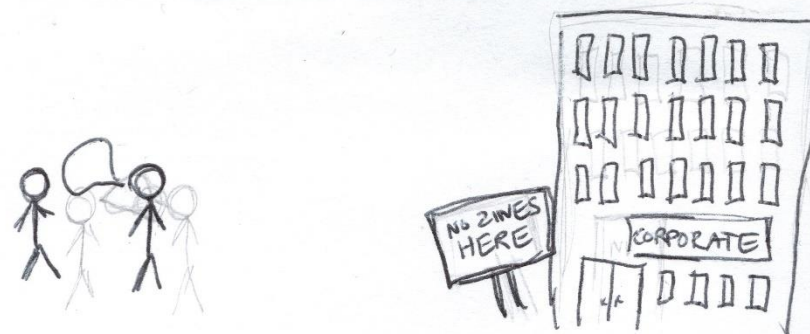
Zines is quite a niche thing. SO for me to say, I want as many people to read it as possible, which I do but I also understand its quite a niche area, so it will appeal to a particular group of people, appeal to a particular community.

(25)

Communication between individuals not with organisations and institutions

And I do think they do raise awareness, but I don't know what I think about. I mean I think their ability to raise awareness is limited because. but I think its huge, but I think its limited to people who are I guess kind of engaged in the culture. Because I think once that starts reaching out too much and it's too corporate there are kind of issues.

I'm on the fence about how useful they are in like other contexts. You know, like more institutional ones



Welcoming

Some survivor zinesters who were marginalised in wider society did not feel they were in the zine community.

But I guess for me it's a community that I've felt very welcomed in, not marginalised in, despite having identities where in mainstream culture I am to some extent marginalised. Um yes. but I think like anything it's not perfect

(30)

Its not all about numbers

Zinesters less concerned with changing views more widely and more concerned with speaking to others who would understand/relate

But if you measure your influence in numbers. It's not. It's not how many people that you reach its the impact not only still takes one person to feel a certain way about something and you kind of your job is done,

I often think like, it wouldn't matter if they ended up in the hands of people who like, didn't share my views or didn't understand, because they wouldn't know what it was about. They wouldn't be able to read it properly so they wouldn't, they just wouldn't get it.

The people I want to read my zines are people who are, like who would relate to my experiences.

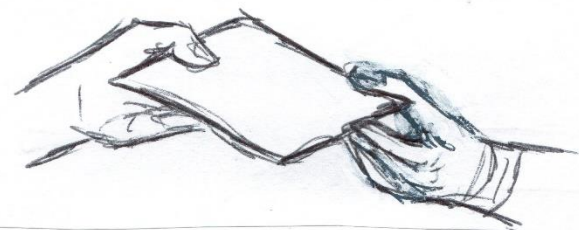
I think zines are great in the community that are attracted to them. I think they are hugely beneficial. in terms of raising awareness I think they are better at providing like comfort to people who are already in that situation, rather than raising awareness with other people.

I TOTALLY
UNDERSTAND
AND RELATE

(29)

I think, with making zines, they are going to be read by a very specific community. So I don't know if they are great for raising awareness – because you aren't going to come into contact with most people, and the people you do come into contact with are probably already singing from a similar hymn sheet!

I also feel like the people that this reaches already have some sort of knowledge of what I'm talking about.



Safety

Being part of an insular community can be a strength as people feel safer to share different types of narratives

"Social convention is a barrier" to accessing "rich raw personal narratives" but not in zines.

But zines also provide that that safe space to do it because it's really a space that's intrinsically there for marginalized voices, you know whatever that means. Because I think when you look at the zines, you don't feel like you are a marginal a voice as much. You know you feel the power, you know the power in the margins.

So, you know people who feel suffocated in wider society they feel like they can breathe again in those spaces they really do. Because they end up saying things they've just been holding back. I think it's similar with zines

(25)

In spoken word and zine community

people talk about really hard hitting topics, homophobia, transphobia, you name it, mental health, you name it

people talk about it there... people (say)... what they want to say, that they haven't been able to say in other places and they may be angry about it, sad about it, happy about it, but they get to say it.

People want to hear it and people are willing to hear it and people are open minded enough to hear it and people understand the need to say that because they feel it themselves and they actually are glad when people say it. They receive it happily.

Whereas in other places:

a lot of people turn their nose up at things or they just say I don't want to hear negativity, or we don't want to hear about this thing that we find disgusting or this thing that we find horrible.

WE WANT TO
HEAR WHAT YOU
HAVE TO SAY

COMMUNITY

(27)

It meant some zinesters felt they knew who other zinesters were, who was in the community and so they felt more able to trust and act on zines they read.

You know the person who made it in a way. You're just like, OK, I know you because you're a member of this community. I know you're part of this so like you don't have to name yourself or be identifiable for me to give weight to what you're saying, to understand the knowledge that you're sharing and to think about the implications of that for my own life, or like join up those dots or take this action or avoid this place you know.

The insular nature of the community can be a limitation to audience/readership

the only people who would look at them, in my opinion, is people who felt the same as me. And so the function there would probably be people who feel seen and heard because they read somebody who is in a similar boat to them or something, or thinking something that they are also thinking.

I just wonder, I do wonder how many people will be motivated to read zines. Like for example, thinking about, you know, for example like some older members of my family, would they pick up a zine, that looks like a zine that I had made and read it?

I guess a lot of zines can end up being quite insular, you know they only end up being shared in the community.

(28)

Appendix 6 Zine and Heard zine

Zine and Heard zine starts on the following page. This is a Word/digital friendly version of this zine, so the pages are in reading order.

Zine and Heard?

A huge thank you to all the people who took part:

Mary Barba
Kirsty Rowles
Rin Flumberdink
LJ
Rosie
Luna Tic
Annie Pocalypse
Dolly Sen
Kira DeSomma
Lisa
Bex
Kazzi
Diane
Nicola
Nazrah

Zine(making) qualities that helped survivors make sense of and/or articulate experiences and interpretations

Visual methods/being able to use images and visual articulation Lisa, Annie, LJ, Luna, Kirsty, Dolly, Bex, Nazra, Nicola and I all said we found this helpful (there doesn't seem to be a difference between participants in stage 1 and stage 2)

Handmade creative process All used handmade processes. LJ, Kira, Nicola, Bex and I highlighted this as important to them/us articulating them/ourselves. Nobody in stage 2 highlighted this but they may not have realised making digitally was an option)

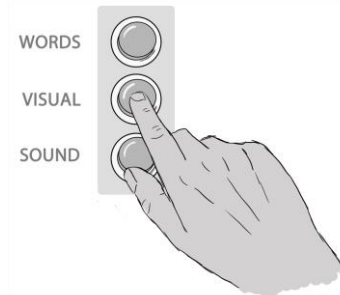
Zines as containers Rin, Kirsty, Annie, Diane, Sophie, Bex, and I all highlighted how being able to use zines as containers helped us articulate ourselves (there doesn't seem to be a difference between participants in stage 1 and stage 2)

Flexible/non-linear structure All participants in both stages made zines that weren't held together by a single sequential linear thread. Annie, LJ, Bex and I highlighted not having to use a linear structure as helping us articulate ourselves.

Why are visual methods important to articulation/sensemaking?

Lisa, Annie, LJ, Luna, Kirsty and Dolly told me that being able to use images and visual articulation was important to them and their preferred method of reflection and articulation.

Bex, Nazrah and Nicola said it was important to be able to use images in their zines

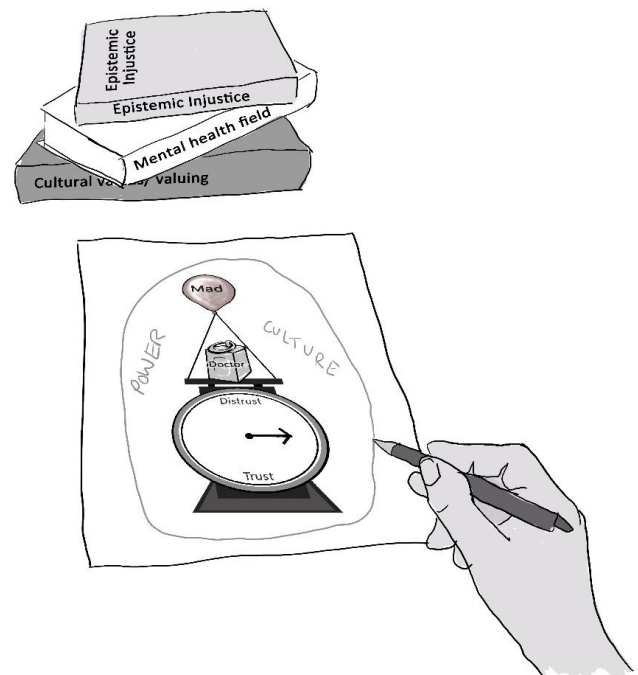


LJ and Lisa said it was helpful to be able to articulate their thoughts visually because they think visually.

Lisa, LJ, Bex, and Nazrah all said they found it difficult to reflect on and articulate their experiences without being able to use images.

In a similar way to LJ, Lisa, Bex and Nazrah, for as long as I remember I have thought visually, and articulated thoughts visually and this is what I am most comfortable and confident doing. I need to use images to reflect on and articulate complex ideas and experiences because for me the process of creating images is the process through which I clarify or arrive at my understanding. This applies to making sense of my experiences and making sense of things I read or hear. (e.g. I draw theories I read about to understand them or to see how they might work in practice).

I see this process like this:



Lisa, Bex and I all struggle to find words for feelings and find that if we can use images, we can more easily articulate emotions and experiences



For Lisa and I the process of making images made us aware of experiences that we wouldn't otherwise have been fully conscious of, let alone able to reflect on and articulate. When I bring emotions, dissociated beliefs and memories into awareness through drawing them I can then reflect on them.

Why is handmade creative process important for articulation?

LJ, Kira, Nicola and I linked making zines by hand to being able to reflect on and articulate experiences of madness, and/or topics that are messy, chaotic or wild.



Rin, Sophie, Kirsty, and Kazzi spoke about their enjoyment of creating zines by hand. Kira and Dolly spoke about their enjoyment of creative processes and Nicola, Diane Annie and Bex related their enjoyment to both the creative quality of zine making and the handmade quality.

Nicola, Bex and I linked our enjoyment of the handmade creative process to being able to reflect on and articulate experiences that were linked with difficult emotions. This was because the enjoyment of the process created a counterbalance to the difficult emotions we were reflecting on and articulating in our zines.

How are zines containers?

Limited size/space (LJ, Sophie, Rin, Kirsty, Annie and Diane)

Limited print run/audience (Rin, Annie, Sophie)

Ephemeral (Rin)

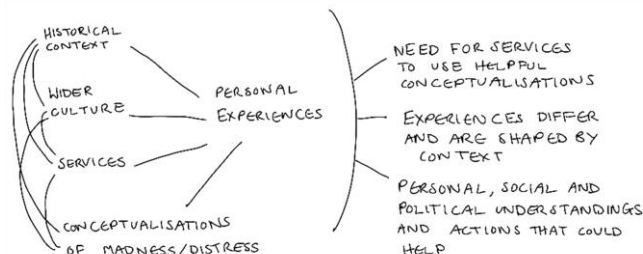
Material (Diane, Bex and Tamsin)



Non-linear structures and articulating context:
Illustration of linear structure/links (based on the stories I've been asked to tell in mental health system)



Illustration of non-linear structure links (based on Annie Psy Trauma zine)



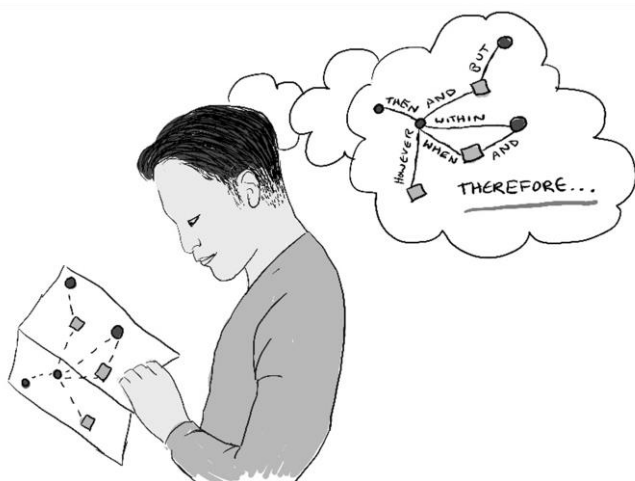
Survivors are more likely to have non-linear experiencing and memory so being able to articulate this is important for survivors.

Being able to loosely, tentatively or implicitly link contents may be useful if people have low epistemic confidence or if they are concerned that their interpretation may be responded to in a negative way.

If we don't understand things through sequencing them, we may be able to understand them by arranging them in different ways and making comparative, contextual and thematic links. Important as survivors are less likely to think sequentially. Also important as it helps create interpretations that are not decontextualised (unlike diagnostic framework).

Perhaps we should think of structures as **interpretive resources** (AKA *hermeneutic resources* (Fricker 2007) *epistemic resources* (Dotson 2012, 2014; Pohlhaus 2012).

Sharing implicit links and sensemaking looks like this:



Experiences like madness are difficult to make sense of and so being able to share the experience without interpreting it means that the experience can be shared, however it might also leave us vulnerable to having our experiences interrupted in a way we don't like.

The relationship between power dynamics and what participants articulate and share

Stage 1 participants told me they shared their zines with: people who bought zines via online platforms (Annie, Lisa, Mary, Kira, Dolly, Rin, LJ, Kirsty), people at zine fairs (Lisa, Mary, Rin, LJ, Kirsty), people who bought from zine distros (Kirsty), and they swapped with other zinesters (Annie, Lisa, Mary), zine libraries (Rin)

These readers might be described as members of the **zine community**.

Some stage 1 participants also shared zines with: friends, who might also be members of the zine community (Sophie, LJ, Kirsty), through activist networks/ spaces (Luna, Dolly), at poetry readings/arts spaces (Kira, Dolly), at a psy conference (Luna) and covertly in mental health services (Luna), and at their university (Rin).

Stage 2 participants shared their zines with other participants (Bex, Nicola, Kazzi, Diane), Tamsin (Bex, Nicola, Kazzi, Diane, Nazrah), a friend (Kazzi), colleague (Bex, Kazzi), mental health art group (Bex)

They shared their zines with people they thought would be interested (Diane, Bex, Nicola, Kazzi), who they thought might understand and value them (Nicola, Kazzi, Bex). They also shared with people with whom it wouldn't matter if they didn't understand (Bex).

What did stage 1 participants say about power dynamics in zines/zine community?

Stage 1 participants Lisa, Annie, Mary, LJ and Kirsty highlighted that zines are shared within the zine community.

Feeling/being unconstrained (Luna, Rin, Sophie, Annie, Lisa and Kira)

Control over the content (Kira, Annie, Rin, Lisa, Kirsty, Annie, and LJ)

Control over process (Annie and LJ)

When making and sharing zines you are not being subject to external control (Luna, Rin, Annie, Lisa, LJ, Mary, Kirsty and Kira)

Making and sharing zines in the zine community:



How did stage 2 participants experience of sharing zines in the zine community differ from sharing with other audiences?

Lack of control in other forms of publishing (LJ and Luna)

Need permission to share in mental health system (Rin)

There are risks associated with sharing in the mental health system (Rin and Tamsin)

Contributions excluded from mental health research findings and from a project recording experiences of a psych hospital (Tamsin)

Literature indicates the agenda/parameters for what can be known can be said to be set by mental health professionals in the mental health system.



In the zine community and away from the mental health system what stage 1 participants articulate and share?

Zines which criticised and/or satirised the mental health system (Annie, Luna, LJ, Dolly and Tamsin)

Criticisms of services/staff in zines that they couldn't/ didn't in mental health system (Tamsin, Rin, LJ)

Negative experiences of services that had been excluded from mental health research findings and from a project recording experiences of a psych hospital (Tamsin)

Anger (Annie, Rin, Dolly, Sophie, LJ and Kira)

Anger at services treatment of survivors (Rin, Dolly, LJ and Tamsin)

Why?

There is less risk sharing anger and criticisms outside the mental health system (Rin and Tamsin)

Less risk:



Why is this important/significant?

Literature indicates survivors' criticisms are not welcome in the mental health system

Anger is not allowed in the mental health system (Rin and Tamsin)

Mental health professionals ignore survivors' anger (Luna and Tamsin)

Articulating anger can help hold on to it and avoid taking on the perspective of mental health professionals (Rin)

What were stage 2 participants experiences of power dynamics when creating and sharing zines?

None of the participants in this stage described the sense of freedom and control described by participants in stage 1

One may have not included gender identity in her zine because she thought it was risky (Kazzi)

These zines were produced in a workshop which was held in the same venue as the support they accessed.

The workshops were facilitated by a researcher as part of a research process

These participants may have been restricted by the context in which their zines were made.

Stage 2 participants didn't share their zines with people who they thought wouldn't understand or value the content of their zine. E.g. Kazzi didn't share it with people who were likely to be homophobic, Bex didn't share her zine with people who didn't have an interest in survivors' subjective experiences, Diane didn't share her zine with organisations who work with children and young people in care as she thought it wasn't the type of information they would be looking for. Nazrah didn't share her zine with anyone other than Tamsin because she felt there wasn't anywhere where the topic of her zine wasn't taboo.

Why and to what effect do stage 1 participants share zines in the zine community?

They know who their readers will be (Kirsty, Lisa, LJ)
None of them said they were unheard of that what they shared wasn't valued in this context.

They expect their zines to be understood and welcomed because their readers will be peers with similar experiences and perspectives to them (Sophie, Lisa, Luna and LJ, Tamsin)

They are choosing to share zines with audiences whom they expected to welcome and understand them.

They are avoiding experiencing testimonial injustice (Fricker 2007), including structural testimonial injustice (2012).

They may be developing shared understanding and a sense of common concern.

Avoiding testimonial injustice may in turn support epistemic confidence (Fricker 2007).

Testimonial injustice in the mental health system:



Structural testimonial injustice:

Choosing audience:



Choosing audience as exercising agency.

Zine qualities and reader reception

The only discernible difference between stage 1 and stage 2 participants use of zine qualities was that stage 2 participants seemed more likely to use unusual physical structures and sculptural elements. This may be because they were making their first (and possibly only) zine and so were not thinking about how it might be reproduced.

How, why and to what effect to participants use visual communication (with and without text)

All the zines research participants shared with me or made as part of this study included a mixture of text and images and/or visual elements.

Some use a combination of text and visual communication because they believed this would increase the chances of readers understanding what they were trying to communicate (Kirsty, Mary, Nicola and Tamsin).

Some participants gained additional understanding via a combination of combination of text and visual communication (Bex, Diane, Kazzi and Tamsin)

Visual communication combined with text helped readers to understand contrasts (Bex, Tamsin, Diane)



Visual communication helped readers understand emotion (Kazzi, Diane, and Tamsin)
 Images on their own could be difficult to understand (Tamsin)
 Readers might understand the emotions but not the context when images are without words



How and why do participants use unusual structures and sculptural elements?

Unusual structures and sculptural elements were metaphors for participants' experiences (Nicola, Kazzi, Tamsin and Bex)

Unusual structures and sculptural elements were intended to give readers a felt sense of their experience (Nicola and Bex)

Confusing structure and sculptural elements were intended to weed out undedicated readers (Bex) Dotson (2011) argues that we evaluate whether our audience is willing and able to hear what we want to share.

To what effect do participants use unusual structures and sculptural elements?

The unusual structures and sculptural elements created emotional and embodied responses in readers (Tamsin, Diane, Kazzi, Bex and Nicola)

Bex's zine

The sculptural elements in Bex's zine gave Tamsin a sense of weightiness and barrenness, a sense of absence, a sense of memory becoming destroyed and fragmented, a visceral sense of what it means to feel constrained and unable to speak and served as a reminder that this was a real-life experience not an abstract idea

Readers felt disoriented in response to unusual structures (Tamsin, Nicola, Diane and Kazzi)

Although readers' disorientation echoed the sense of disorientation Bex felt in response to the death of her therapist (which was Bex's intention) readers did name the connection between the zine topic and the feeling of disorientation and so may not have been conscious of it although it may still have added to their understanding.

The sculptural elements of Bex's zine made some readers feel uncomfortable/unsure about reading it (Diane, Kazzi, and Tamsin)
 In response to the sculptural elements readers may not have read it thoroughly and missed details that were important to Bex because they didn't want to be intrusive (Diane and Kazzi)



When it was emphatically communicated that the zine should be fully explored and read then that is what happened (Tamsin)

Kazzi's zine

The sculptural elements in Kazzi's zine gave a visceral sense of urgency, inevitable uncontainability and joy (Diane, Bex and Tamsin).

What did zines being a creative object enable?

Some participants use zines as a creative object to create distance between themselves and the content of their zine (Annie, Bex and Tamsin)
 This created a sense of safety/containment (Annie)
 It enabled participants to share things they felt were difficult to share or taboo (Bex and Tamsin)



What is the relationship between culture, what participants share and how this is received?

Participants from stage 1 said by making and sharing zines they were opting into a specific culture
 This culture was described as being created by and for people who were marginalized elsewhere (Dolly and Annie)
 This culture was described as *non-mainstream* (Luna and Annie), *queer* and *political* (Annie), participatory (Rin)
 Making and sharing zines was contrasted with how mainstream mental health campaigns replicate dominant and conventional ideas of mental health (Annie)
 Making and sharing zines was described as a process of valuing *esoteric knowledge* (Luna)

Stage 1 participants described making and sharing zines as reducing shame (Dolly, Annie, Sophie and Tamsin)

Being mad or having a different mind was linked to experiences of being shamed elsewhere (Dolly, Annie and Tamsin)

Experiences of being in psych hospitals were linked to being shamed and being unable to trust their own voice (Annie and Tamsin)

If we have been in the mental health system someone has decided that who we are in some way violates cultural norms.

Shame is silencing

That participants from stage 1 described making and sharing zines as reducing shame suggests the culture in which they share their zines is one in which they don't violate cultural norms (i.e. it is culturally acceptable to be mad, traumatised or neuro divergent etc within the zine community).

Stage 1 participants linked making and sharing zines to feeling confident or having increased self esteem

They linked making, sharing and reading zines to increased self-esteem and confidence in their voice (Sophie, Annie and Tamsin)

In contrast experiences in/of the mental health system had made it difficult for them to trust their own voice (Annie and Tamsin)

They spoke about needing to boost confidence after experiences of being silenced and/or their accounts of experience and understandings not being valued (Annie, Mary and Tamsin)

That participants from stage 1 linked making and sharing zines to feeling confident or having increased self-esteem and contrasted it with experiences of their contributions being silenced/unvalued, suggests the culture of the zine community is one in which survivors understandings and accounts of experiences are valued.

Stage 1 participants described a culture in which survivors accounts of their experiences and their understanding were valued

Participants spoke about people learning from their zines. (Lisa and Sophie)

They felt their contributions, the experiences and understandings they shared were valued (Annie, Mary, Rin and Kirsty)

They spoke about having gained new ways of using language and new ways of thinking about mental health experiences from reading other survivors' zines (LJ, Dolly and Mary)

Zines might be dismissed by people who don't usually read zines, i.e. people who were unfamiliar with the culture (Dolly and Annie)

None of the participants described survivors being ignored, unheard, not being taken seriously or being regarded as lacking in credibility by people in the zine community.

Why might survivors accounts and knowledge be valued?

Identity is complex, we are not just survivors
Valuing subjective knowledge and recognition of importance of context

Stage 1 participants described a culture in which the complex identities are recognised

Identity is recognised to be multifaceted (Rin and Tamsin)

They were not perceived exclusively, or even primarily, in terms of their service user or mental health status (Dolly, Sophie, Rin, LJ and Kirsty)

Conceptualisation of identity in the mental health system:



How identity is conceptualised is important because being able to write about ways in which identities intersect is important for knowledge of intersectional experiences. It is also important because how identity is conceptualised is linked to how survivors can be perceived.

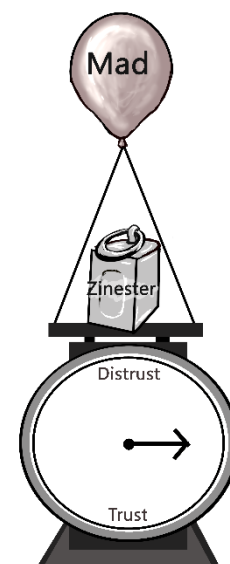
What is the effect of interacting with a culture in which identity is not conceived in terms of mental health status and service use? (stage 1 participants)

This was linked to zines enabling them to raise awareness of how systems of inequality intersect (Dolly and Tamsin)

They didn't have to write about only one aspect of their identity and experience when making and sharing zines (LJ, Dolly, Lisa, Kirsty and Rin)

They could be seen, and see themselves in terms of their capabilities and strengths as well as their survivor status (Sophie, Dolly and Tamsin)

The effect of being perceived as a mad zinester:



Even if it's not shameful to be a survivor in zine culture it may still be linked to use being perceived as less credible.
Zinester identity balancing out mad identity.

Not having to fit into conceptualisations created by the mental health system means that instead knowledge can be centred around understanding an individual's experience (Annie and Tamsin)

What types of knowledge are recognised and valued? (Stage 1 participants)

Subjective contextual knowledge is valued (Sophie and Mary)

Through zines participants learn from and share knowledge of specific experiences without generalising from these (LJ, Lisa, Luna and Kirsty)

This contrasts with what we know of the mental health system.

Participants also contrasted this with mainstream media (Kirsty and Lisa)

You could say that in the zine community there is a culture of recognising and valuing multiple subjective truths (i.e. it's based-on interpretivist ontology and constructionist epistemology)

What is the link between zine culture, zines and (epistemic) authority? (Stage 1 participants)

Informal knowledge and ways of knowing as being valued in the zine community (Lisa, Annie, Luna and LJ)

Zine readers trust and act on the knowledge in zines because there is a sense of personal connection, and accountability because they are from the same community (LJ)

Zine making is about personal connections not hierarchies.

Within the zine community the handmade nature of many zines aids the sense of trust and the authority awarded to zines.

Zines differ from digital media because you don't have a sense of who has made digital media, or even if it was made by a person (Lea).

Making zines by hand was linked to creating personal connections with readers (Luna, Annie, LJ, Rin and Sophie)

They are relying on *relational authority* (Bradley 2001 p.7).

Outside of zine culture survivors accounts and zines are not valued in the same way (Stage 2 participants)

Handmade mediums are not expected to be valued outside of personal contacts and certainly not in/by services (Bex, Nazrah, Dianne and Kazzi)

Authority in zine culture (Stage 1 participants)

They linked zine culture to not seeking *institutional validation* in zine culture (Lisa and Annie)

Zine culture was linked to valuing knowledge that isn't formal or academic (LJ)

They chose to make zines was because there wasn't an expectation that knowledge should be formally or institutionally recognised to be valued in the zine community (Annie and Luna).

They were suspicious of institutionally produced/funded media (Kirsty)

Informal survivor created language and concepts are shared and valued in the zine community (Luna, Annie and LJ)

This was contrasted with being expected to use formal and clinical language and concepts in the mental health system (LJ)

When trust and authority is awarded because the information hasn't been institutionally produced this has been called *vernacular authority* (Howard 2013).

None of the survivors I spoke to described being disadvantaged by a reliance on conceptual resources and language created by and for mental health professionals in the zine community.

All participants included lived experience and first-person perspectives in their zines.

"the point of zines is about the importance of the personal and the linking of things to your life" (LJ)
You might say that in zine culture there is a valuing of what Brady (2001) calls *experiential authority*.

Authority (Stage 2 participants)

Participants from stage 2 who were unfamiliar with zine culture included institutionally produced information in their zines (Diane, Kazzi and Nicola)

The motivation for this appeared to be to add authority (Diane and Kazzi)

You might describe them as drawing on institutional authority in their zines. If someone doesn't have access to a community/culture in which experiential non-institutional knowledge is valued, then it makes sense to draw on external authority in an attempt to be heard and have what you know to be true to be valued.



In contrast, where the participant from this stage who was familiar with zines and zine culture included institutionally produced information, she foregrounded her experiential knowledge and showed the institutionally produced information as lacking (Bex)

By sharing their zines with people they know personally in the community in which they live and/or work stage 2 participants may be relying/capitalising on relational authority (and possibly experiential authority)

When I first started making zines I often included quotes from research or references to this, which was in part because I found it difficult to imagine a culture in which I might not need to draw on institutionally recognised knowledge, theories and language. It has only been through reading more zines, attending zine fairs and speaking with people who make and read zines that I have become acclimatised to the idea that non-institutional (vernacular) knowledge is/will be awarded authority in the zine community.