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"POWER MAKES US SICK"

How Mental Health Activists in London Heal through Indeterminate Worlds
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Declaration

I certify that the thesis I have presented for examination for the PhD degree of the University of Kent is solely my own work other than where I have clearly indicated that it is the work of others (in which case the extent of any work carried out jointly by me and any other person is clearly identified).

The thesis consists of 90599 words.

I. Abstract

This thesis is based on 13 months of ethnographic fieldwork with groups of mental-health activists in London. As past or current patients of the National Health Service, activists self-identify as 'survivors', 'evaders' and/or 'ex-users' of formal mental healthcare. These terms express how engagement with services has left activists with a profound sense of grievance and disquiet. In accounting for their views, activists decry the dominance of the biomedical model, the invasive managerial systems, and the insensitivity of clinical encounters, some of which involve force. They also protest that access to welfare benefits is determined by mental-health assessments. I explain the lingering affective and phenomenological presence of biomedicine in activists' lives by describing it as a 'shadow'. This shadow manifests in activists' histories and narratives and also informs and unsettles their present. Reliant on a system of mental healthcare whose tenets they reject, activists are caught between conflicting subjectivities. While activists strive to assert their autonomy and competence and call out epistemic violence and injustice, the biomedical system positions them as incapacitated and vulnerably dependent, in turn discounting their concerns and corroding their sense of independence.

This is the context in which activists come together to forge their own modes of healing by building indeterminate worlds. Worldbuilding is the everyday relational and spatial practices and ways of being, which in the case of mental-health activism are founded on mutuality and indeterminacy. Building healing worlds around these attributes allows activists to enact alternative social and political imaginaries, or live 'the change they wish to see'. In the process, activists seek to re-frame their lives and relationships by making spaces to 'be' and 'become', and to 'go through madness' together. Thus, activists resist the drive toward coherence or consistency in mental health services; this allowing them to prefigure a more subjective, inclusive and adaptive approach to mental distress that permits plurality, alterity and autonomy. In other words, activists heal according to their own terms. This is not to imply that activists' relational practices are invariably consensual and cooperative, since mutuality, and indeterminacy entail much complexity, contradiction and much uncertainty. Moreover, when activists experience the suffering of others, this can become enmeshed, and even indistinguishable from their own distress. Nevertheless, I conclude that conflict and mutual hurt are not simply sources of suffering, since they also generate a sense of safety and connection and as such, are constitutive of the kind of mutuality activists enact. In making this case, my thesis contributes to debates in medical and political anthropology as well as mental health and Mad studies.

This thesis is dedicated to the memory of Pete Coward

Rest in Power

II. Acknowledgments

III. Glossary of terms and acronyms

Care-Co-ordinator- The clinician responsible for a patient's care plan, usually a social worker or mental health nurse.

CPA- Care Plan Approach- A standardised 'framework' document consisting of a care 'package' identifying the responsibilities of clinical teams for patients in secondary mental health services.

CQC- Care Quality Commission- The regulator of health and social care in England.

CMHT- Community Mental Health Team- A secondary mental health services multidisciplinary team that treats patients in the community.

DH – Department of Health and Social Care – the ministerial department responsible for the UK's health and social care systems. Used to be named 'The Department of Health'.

DWP – Department of Work and Pensions – the ministerial department responsible for pensions, welfare and child maintenance grants.

DSM - Diagnostic and Statistical Manual of Mental Disorders - a publication by the American Psychiatric Association for the classification of mental disorders used worldwide.

EBM – Evidence-based Medicine- based on research from RCTs.

ECT – Electroconvulsive Therapy- a form of treatment in which electromagnetic currents are used on patients to treat for 'severe' or 'treatment resistant' depression.

ESA – Employment Support Allowance- a welfare payment for adults who cannot work due to illness and/or disability. It is being replaced by Job Seeker's programmes as part of a government move to increase the employment of people on long-term benefits.

IAPT - Improving Access to Psychological Therapies- An NHS initiative to provide more psychotherapy to the general population, assessed by standardised questionnaires.

Iatrogenesis- refers to unintended harm done to a patient through medical treatment. Activists use the term often when referring to the consequences of TAU.

Mental Health Act assessment- informally known as a 'section;' a procedure in which mental health professionals decide if a person can be detained or treated compulsorily.

NHS- National Health Service- the UK's publicly funded healthcare system.

PIP- Personal Independence Payment- a welfare payment contributing to the extra costs associated with living with long-term disabilities.

RCT – Randomised Controlled Trials - A form of evaluation to test medicine.

SSRI- Selective Serotonin Reuptake Inhibitors—a common form of anti-depressant

TAU – Treatment as Usual – Used both in mental health practice to describe standardised treatments, and by activists as a critique of those treatments.

UC- Universal Credit – a social security payment which is replacing six other benefits (including ESA, Disability and Housing Benefit).

Specific terms[1]

Patient- a person in receipt of biomedical treatment

Service-user- a person in receipt of biomedical treatment, who is amenable (uncritical of) the idea of using mental health services, *or* who is required to use them in order to receive welfare benefits

Service Consumer- a person in receipt of biomedical treatment, who is critical of mental health services, and understands services to operate in the form of a market-based economy

Service Evader/ Ex-patient- a person who intentionally avoids mental health services, who may at times, be forced to use them due to welfare benefits, or lack of other available resources.

Service Survivor- a person who has experienced biomedical treatment they found to be iatrogenic, and positions themselves as a survivor of mental health services

Survivor – shorthand for either service survivor, or survivor of Psychiatry- a person who rejects psychiatric practice and found it to be iatrogenic.

Survivor Researcher – usually a researcher who identifies as a Survivor, who abides by a particular manifesto, agreeing to support the mental health activist cause through research and dissemination activities wherever possible

C/S/X – (consumers/survivors/ex-patients) common collective shorthand for the mental health activist movement

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[1] I have provided basic definitions here, but these terms are fluid and changeable according to context. Individuals adapt these terms according to their own personal histories, experiences, and circumstances.

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The Curse of the Paper Self

A person could be crushed to death under the weight of their notes but still not have received any sort of meaningful care. After a while, it feels as if you actually cease to exist, swamped by this paper version of yourself which somehow takes on its own life. After a while, it is your "paper-self" who is risk assessed, diagnosed, and treated. After a while, you realise there's nothing you can do to stop the rise of your paper-self, because every word, every action, every movement you make only adds to its ever-growing and everlasting presence… I was completely aware that while services had succeeded in sculpting a new person made entirely of paper and ink, they ultimately believed that person to be me.

Extract taken from: Mental Health Clinical Notes: The Curse of the Paper Self, WrenAves (2021)

V. Prologue

"We need to develop a culture of madness… where people can go through journeys as individuals and heal themselves" – Bryan (2013).

"We are the antibodies to the disease" – Janet (2019).

In *Suicide*, Durkheim (1897) argued that good mental health is facilitated by strong social ties. According to this view, personal liberty, autonomy, individual interest and self-governance erodes those ties and are therefore detrimental to mental health.[2] Contrary to this interpretation, this thesis is about how mental health activists forge healing worlds through the merging of collective sociality *and* individual autonomy, as the above quotes indicate.[3] I show how activists allow one another to act freely, out of self-interest, yet at the same time, take responsibility for supporting one another, creating worlds in which this novel combination maintains lives.

My masters' dissertation examined the emergence of collectivist values and the building of community at Occupy; a global social movement that condemns the unequal distribution of power and resources in capitalist societies.[4] I explored how people who have participated in so-called neoliberal forms of sociality prefigure their worlds around egalitarianism and anarchy. During fieldwork, in 2011, I found myself volunteering in the 'tea tent' at the Occupy London protest camp outside St Paul's Cathedral, in the heart of London's banking district. The camp was set up as a site of anti-capitalist protest and an experiment in democratic and egalitarian communal living. Given the strategic location,

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[2] Specifically, Durkheim discussed how people transfer moral feeling and responsibility through sociality.

[3] In this thesis I use 'mental health activist' and the 'mental health activism movement' as an umbrella term to refer to individuals involved in a wide array of activities that are focused on changing the UK's approach to mental health—some of whom are also interested in anti-capitalism. I use other, more specific, terms, such as 'survivor', as and when these are used by interlocutors. Full clarification of these terms can be found in chapters 1 and 2.

[4] In October 2011, protestors attempted to 'occupy' the London Stock Exchange but were prevented from doing so. Following this failed attempt, they moved to land adjacent to St. Paul's Cathedral (chosen because it is an iconic tourist spot), where they remained until the end of February 2012. The number of residents at Occupy varied greatly over time, from a minimum of ten, to on occasion, several hundreds. The tented community was largely sustained by donations from the public and local businesses. Tents and temporary shelters were set up to meet accommodation needs and voluntary working groups were set up to manage different aspects of daily life, such as recycling, sanitation, and financial administration.

Occupiers were unsure how long they would be allowed to remain on the site, yet the encampment lasted a full five months. As winter neared, the conditions became increasingly difficult and feeding and hydrating the five hundred or so people who were living at and visiting the site each day was challenging. Initially, I thought that by making cups of tea and chopping vegetables in the tent kitchen I was where the need was greatest. But I soon realised that there was an abundance of volunteers in this role. At the same time, discussions at Occupy General Assemblies[5] regularly touched on concerns about high rates of 'burn out' and mental distress among camp members. As well, people from outside the original occupying group, many of whom were rough sleeping, came to the camp in search of food and shelter, or a place to rest and relax in the company of others. Some of these individuals were in acute states of distress. Thus, even though most camp occupants were there out of political commitment and self-defined as anti-capitalists, a significant and growing proportion were also in search of solace and recuperation.

Things came to a head one day when a volunteering psychiatrist on site rang another psychiatrist to section an activist following a heated argument he had had with his dead mother. The psychiatrist's action caused an uproar, and it quickly became apparent that this was not how camp members would expect to manage these kinds of situations. The psychiatrist had not consulted the community on how best to respond to the man's outburst; nor had he sought the man's consent to the sectioning. He was accused of addressing the situation according to his own, rather than the community's, understanding of mental health, and of breaching one of the community's key principles—that all aspects of community life should be managed by community members without external intervention. He was also censured for prioritising his own interests above those of the man he had sectioned, his motive for the sectioning being perceived as more about fear of the trouble a disturbed individual might cause than helping alleviate the man's distress. The psychiatrist was eventually asked to leave the camp.

It was around this time that Occupy's 'Welfare and Wellbeing' group was born; thus began the second of several 'phases' in the community's evolution as a social movement oriented around mental health and politics. A small, group of volunteer Reiki healers,

[5] Occupy's primary form of governance, 'General Assemblies' were held daily, and all Occupiers expected to participate. The Assemblies provided an opportunity for Occupiers to make decisions based on consensus (c.f. Howard and Pratt-Boyden 2013).

psychotherapists, psychologists, social workers, neo-shamans, counsellors and laypeople, decided there was a need to respond to the mental health needs of Occupiers by consolidating an informal, collective approach to healing within the camp. They tried to create a welcoming environment by erecting a tent, furnishing it with soft lighting and cushions and designating it as a quiet space where people in distress could sit in peace and comfort. Volunteers managed the tent on a shift basis and maintained a 'logbook' detailing who visited, when and why.[6] Yet, despite their efforts to provide a safe and supportive space in which all Occupiers were welcome to spend as much time as they wanted, most people seemed wary of visiting the tent. There was talk in the camp that the space was too exclusive. It was likened to a conventional therapy room in which interactions were perceived as private and individualised and therefore, somehow dangerous. Acknowledging that they needed to do more to promote their therapeutic approach, the volunteers began to focus more on community outreach and engagement. Their aim was to generate an understanding among camp members that mental wellbeing and healing are a collective responsibility in which everyone can and should participate. They held several seminars on Psychopolitics[7] and led discussions on how to embed a more community-oriented approach to healing within the daily routine of the camp. Walking purposefully around the community, they made an effort to get to know camp members, whenever possible addressing people's needs on the spot. They offered a range of measures, including conflict de-escalation, co-counselling and 'healing circles'.[8] Gradually, camp occupants began practicing this emergent community approach to healing themselves, rather than resorting to medical intervention.

Another major transition occurred early in the spring of 2012, when the police finally evicted Occupiers from the St Paul's site and the camp was destroyed. The day of the eviction was tense and emotionally charged and there were a number of arrests. Not all of the activists were prepared to bring their protest to an end. Among other follow-up initiatives, a small group of like-minded Occupier volunteers decided to continue the

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[6] As many of the volunteer professionals were used to working with individual clients in private settings (such as therapy rooms) they set up a shift rota to ensure that there was a volunteer present at all times. It was expected that people would visit the tent and take turns in having private, one-to-one sessions with whoever was on call.

[7] The examination of how politics and political structures affect psychology (See Sedgwick 1982).

[8] Developed initially by First Nation North Americans, encircling is fundamental to their spirituality (see Calabrese 2013). At Occupy, this technique involved people who were known to and trusted by an individual in distress quietly surrounding that person and offering them support through silence and/or physical holding. A voluntary action undertaken by individuals who happened to be present when someone was in distress.

system of collective mutual support they had established in the Occupy Camp. They created an offshoot of the 'Welfare and Wellbeing' group and labelled it 'Occupy the Couch'.[9] As with other social movements, such as #MeToo and Black Lives Matter, mental-health support at Occupy arose in the context of debates around the subjugation of marginalised social groups, resistance to conventional power structures and the fight for empowerment and justice. Thus, political activism and living 'the change you wish to see' were, and continue to be, central tenets of this initiative. A few Occupy the Couch members moved together into a squat with the intention of continuing to live out their political beliefs and communal healing approach, constructing an explicit 'community' organised along lines that were distinct from 'others'. Even though the group has since been evicted from the squat, its members continue to engage actively in a range of mental-health networks throughout London. Some are sleeping rough, but most are lodged in council-funded accommodation or supported housing.[10]

"You can't evict an Idea"[11]

Although I had not set out to study mental health or mental-health activism I became increasingly interested in the experiences, perspectives and practices of the Occupy the Couch members and other groups engaged in similar activities. At Occupy, I was struck by how antagonistic relations appeared to be—solidarity and consensus seeming less common than dispute. Yet, I also found that despite high levels of conflict, people were trusted and readily accepted into the group, regardless of their conduct; this generosity of spirit was extended not only to Occupiers but also to strangers outside the community. I also noted an apparent contradiction between the stressful, transient and unpredictable camp environment and what I at first dismissed as the highly romanticised way in which protestors talked of their community. Though protestors seldom articulated their philosophy verbally, they remained living together for a long time. Their commitment to communal living remained unshakeable, despite the harsh winter, months of tension and 'in-fighting', cases of sexual harassment, theft, relationship breakdowns, and overall general exhaustion.

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[9] This move consolidated the group as having a de-colonial approach to therapy.

[10] Prior to their eviction (from both Occupy and the squat) some had given up their jobs and supported subsidised government accommodation to live together. Without the support of the network, more would be sleeping on the streets and others would be in psychiatric wards.

[11] This is a common rhetoric discussed by Occupiers post eviction- the premise was that despite being physically disbanded, the eviction of the Occupy camp did little to avert the movement.

Throughout all of this, I watched activists who were themselves exhausted, take on extra duties when their friends were struggling and at risk of suffering 'activist burn out'. I observed them care for a woman who was experiencing an acute mental-health crisis, sitting with and talking to her, staring into her eyes and smiling at her for three whole days and nights while she remained unable to move, speak or eat. I saw activists attend to another elderly woman all night long in shifts. She wet herself frequently and the smell of her urine was so strong that they wore nose plugs as they slept by her side. The ways people were talking and behaving in the community were imbued with compassion, warmth and emotion. Most members of the group endured acute resource limitations, recurring periods of ill-health and high levels of uncertainty and stress—the latter often occasioned by difficult encounters with welfare and mental-health regimes. Their commitment revealed extraordinary resilience, leading me to question how activists manage to sustain such compassionate relationships in the context of so much hardship and struggle. In particular, I wanted to learn how people from disparate backgrounds and with diverse life experiences are able to build and sustain a sense of community given their precarious circumstances. Beyond this, I was keen to understand how activists' engagement in transformative political action shapes and is shaped by their commitment to developing an alternative, informal, approach to healing—a circumstance that is especially challenging given that many activists regard themselves to be 'survivors' of punitive mental-health treatments and yet continue to depend on those same treatments to access welfare benefits.

Eventually, I decided to undertake doctoral research focusing on mental-health activism. Although my doctoral research included interlocutors from a range of activist networks, it also included several of the activists I had first met at the Occupy Camp a decade back.[12] I sought to understand what it means for my interlocutors to be an 'activist' (this implying a degree of self-assurance and autonomy) and mentally distressed (and therefore, seemingly, vulnerably dependent) at one and the same time. Contending with multiple, apparently contradictory, subjectivities can be particularly challenging for activists who protest against mental-health services whilst also being users of those same services. In the thesis, I track the concurrent and intertwining experiences of activists' subjectivities

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[12] The Occupy movement has had an enormous influence on the understandings, values and motives of many of London's mental-health activists (see Pratt-Boyden 2012). 'Occupy' lives on through various networks that to this day remain active and in contact with each other.

and show how the 'identities' of protestor and patient cause problems for activists in being taken seriously, both by providers of mental health services, and even in research.[13]

My interest in this particular issue emerged out of a conversation I had early on with Andy, one of my key interlocutors. When I first introduced myself to Andy and explained that I was studying mental-health activism he seemed surprised. "Really?" he responded excitedly and then added, "usually researchers and people are only interested in hearing about us as mental persons. They love hearing stories about us *being ill*. In fact, I think they get off on it". Andy was one of the first people to alert me to the fact that mental-health activists struggle to be recognised as amounting to more than their 'illness'. As I got to know Andy, I found him to be kind and thoughtful, with a wry sense of humour—a writer who has recently been working on his memoir. He was born and grew up next to a naval base in a remote Scottish community. The memoir contains a number of proud poems about Scotland, addressed to the First Minister of Scotland, Nicola Sturgeon. Andy had a difficult childhood. His father died when their house burnt down and, aged just 8 years, Andy took a series of jobs to help his mother out. His classmates teased him for being effeminate—most likely because he was fatherless--and they jeered each morning as the school bus passed his burnt house. In his teens Andy got a job at one of the military bars, some sailors having witnessed him break up a fight between their peers and a group of locals and being impressed by his ability to diffuse tension with jokes and storytelling. Andy later moved to London, where he met his wife. They had a son, though are now separated. In focussing on that which brings activists together; - I do not want to suggest that mental distress and mental-health activism are the only (or indeed most important thing) in interlocutors' lives, or for all activists. Activists live full and varied lives. However, the amount of time interlocutors spend in the company of other activists and dedicate to activism suggests that for many, it is hugely significant. As I demonstrate, activists gather on Christmas day, for birthdays, funerals and births—often opting to be in each other's company rather than that of family members. I hope to shed some light on the diversity of activists' experiences; including the ways in which they live lives through, for, and with one another.

Andy describes himself as a 'revolving door patient'. He has been diagnosed with schizoaffective disorder. His doctors believe he can 'recover', but make clear that his

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[13] I refer to activists and others specifically as 'patients' specifically to signify their subjectivity at particular points in time as recipients of biomedical treatment.

recovery is contingent upon accomplishing certain objectives, including communicating properly with medical staff, taking the anti-psychotic drugs he has been prescribed, and keeping both himself and his flat clean and tidy. Yet, from one of Andy's psychiatric appointments, it was clear to me that none of these things matter to him—indeed, the appointment seemed to leave him with a lot of unmet 'need'. He was far more concerned about his best friend's death and the impact this was having on his friend's son. He was also very upset about climate change and the fact that the nurses who had visited him at home did not ask how he was feeling or help him tidy his flat. Andy finds the constant pressure to achieve milestones that he does not agree with and do not help his recovery incredibly frustrating. Worse, he sees these psychiatric meetings as a waste of time and resources as they entirely miss the point; he feels coerced into following certain treatment paths simply to avoid being evicted from his flat (something health professionals often threaten him with).

Andy's experiences of and designation as a 'revolving door patient' resonate closely with many of the other activists I introduce in this thesis. Their rich and complex lives are often reduced to needs, pathways, strategies, and targets. Andy is constantly being pushed in one direction by the mental-health and social-welfare regimes and is caught between conforming with the trajectory required by these regimes and doing things—like activism, writing, meeting friends for tea, etc.—that actually make him feel better. Andy struggles to convince the people who manage his care that he is more than a 'schizophrenic', 'treatment objective', 'recovery path', or the state of his flat. I argue in the thesis that many of the activists I encountered seemed to want, and need, something other than TAU mental-health treatment, something 'otherwise'. Activism means many different things to different interlocutors, but most agree that it is not just necessary, but *vital*. Thus, when I asked Janet, a patient, independent mother of two, why she had been involved in activism for nearly a decade she replied, "because I would not survive without it". Activism is not just a by-product of life; it is a necessary part of living.

That interlocutors regard activism as essential for their wellbeing is not surprising given how death frequently comes early to people with mental-health problems. Patients on anti-psychotic drugs over the long term are 34% more likely to die younger than average (c.f. Goff et al. 2017). Individuals being treated for schizophrenia have an average life expectancy that is 10-20 years shorter than the average person in Europe (Hjorthøj et al. 2017; Laursen 2014). Since I left the field in 2018, to the time of writing, four of my

interlocutors have died, and two other important figures in mental-health activism also lost their lives—-a circumstance aptly summed up by Julie, "too many survivor deaths". People with long-term, or chronic, mental illness often occupy marginal social and economic positions in society. Thus, high rates of obesity among schizophrenics are attributable in part to the side effects of anti-psychotic drugs and partly to chronic poverty and stress.[14] In this thesis I show how interlocutors' personal struggles with mental distress, poverty and livelihood insecurity are intensified by the many challenges they confront in their interactions with state mental-health and social-welfare services. Years of changing horizons and slow suffering under austerity (Jupp 2022) and associated budgetary and service cuts have taken a toll on mental health in the UK. For example, a significant number of deaths among people on benefits appear to be linked to benefits sanctions and other Department for Work and Pensions' (DWP) activities, such that in May 2021 an inquiry into this situation was opened (Homer 2021). Further, between 2011 and 2014, 2,380 benefits recipients died shortly after being formally declared able to work and removed from the welfare system (BBC 2015; The Guardian 2015).

During fieldwork, interlocutors often invoked DWP policies as causal in mental breakdowns and also described the extreme anxiety brought about by forced hospitalisation and other such treatments. I therefore highlight in the thesis the importance for my interlocutors of healing justice, as well as the centrality of current mental-health and social-welfare policies in aggravating, rather than preventing or ameliorating, their mental distress. I do this through a series of vignettes that explore interlocutors' encounters with specific regulations, policies and treatment pathways. I also examine the ways in which they attempt to 'distance themselves from what has already been' by re-configuring the experience of being mentally ill and dependent on benefits.[15]

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[14] The borough I conducted most field meetings in has the highest child poverty rate of all London boroughs.

[15] I am aware that in representing mental healthcare in the UK from the perspective of activists my thesis conveys a particular set of experiences and understandings and appreciate that these are likely to differ markedly from the views of many policy makers and clinicians. I am also conscious that many service providers have their own concerns about the present state of public mental healthcare in the UK and that the approach, quality, coverage and impact of mental-health provision varies widely by region, provider and other factors.

VI. Introduction and Theoretical Framework: Healing, Mental Distress, Politics and Sociality 'Otherwise'

VI (i) Chapter introduction[16]

In this introduction I outline the key concepts underpinning my thesis. In trying to understand mental health activists' configurations of healing through therapeutic sociality, I resist providing answers and solutions to this complex phenomenon. As I show, activists' approach to healing is intentionally vague and indeterminate. To make this case, I integrate the literatures on social movements, social justice and political philosophy with theoretical work in medical anthropology to generate a deeper understanding of healing practices in politicised settings. An examination of how activists' build their worlds brings the importance of politics and political perspectives, as well as activist understandings of health, ill health and healing environments, to the fore. By revealing how among mental health activists' healing cannot take place without struggle and suffering, I challenge literature which ignores the distressing effects of activism in favour of the positive relations of solidarity it creates (cf. Juris 2008; Graeber 2004; Eckert 2019; Perl 2021), as well as critiquing the literature that argues that kinship and care are sites of 'unconditional amity' (c.f. Sahlins 2011: 235).[17] In doing so, I contribute to the anthropology of mental health regarding the multiple and nuanced ways healing is experienced. For activists, it is not the case that sociality is consistently and unambiguously positive, nor that negative forms of sociality (conflict, pathology etc.) exist somehow *outside* of social life. This idea is a legacy of a specific set of social expectations that come to us from Durkheim and others (c.f. McKearney 2021) who argued that an emphasis on autonomy erodes social relations. Rather, I show that theories in which individual autonomy is conceived as harmful to collective sociality and therefore also to mental health, do not apply in the case of activists because they regard fostering the expression of individual autonomy *collectively* as healing. Enabling individuals to 'be themselves' in the company of others strengthens

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[16] Parts of this chapter draw from, and are continuations of my MSc thesis (Pratt-Boyden 2012).

[17] Indeed, studies of social movements have been criticised for generating "grand universal theories" rather than looking at their specific environs (Sutherland 2013; 613). For example, the theory of 'collective action', in which movement actors are perceived to be mobilised systematically by unity, has been criticised for its universalising design. There has also been a call for anthropologists to be more engaged in social movements, particularly in regard to the informal networks, ideological differences, and internal tensions (Edelman 1999) that often exist within movements (See Jenkins 1988; Edelman 1999, Brodkin 2005 and Thomassen 2012).

social ties. In making this case, I add to studies about therapeutic sociality and transformative mental health approaches, practices and environments that diverge significantly (and occur outside of) those employed in conventional Euromerican clinical settings.[18]

I begin the first section one with a broad outline of the key theoretical concepts and frameworks underlying the thesis, informed by anthropological approaches to mental illness. I introduce some of the main ideas behind my conceptualisation of mental illness (which I term 'mental distress'), which are largely based on activists' experiences and theoretical and empirical work in medical anthropology. I trace theories related to the social meaning, origin and impact of mental distress, addressing key debates concerned with social defeat and structural violence. I introduce the concept of the 'shadow of biomedicine' to highlight the affective and phenomenological presence of past experiences which constantly inform (sometimes even interrupt) the present for interlocutors. I explain the term 'distress' through an epistemic injustice lens, also outlining why I use this term instead of 'mental illness'.

In the second section I explore social movements, arguing that they are settings in which actors build worlds.[19] I address debates in social movement scholarship, which centre on the *possibilities* that actors have to 'live the change [they] wish to see in society' (c.f. Graeber 2013; Maeckelbergh 2011). I investigate the notion of 'prefigurative' politics, in which actors live out alternative, desired futures. I also discuss 'otherwise' politics, in which living conditions limit the emerging potentialities of political engagement. I argue that, together, the different facets of activists' networks - mutuality, attunement, and indeterminate political organisation - encompass the means by which interlocutors create healing worlds.

In the third section I outline how healing is part of prefiguring a different way of living alongside mental health and other challenges. Healing for activists is the diffuse process

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[18] Research that does exist on Euromerican mental distress and therapeutic sociality focuses predominantly on the experience of schizophrenia (e.g., Eliacin 2013; Jacobson 2001; Jenkins & Barrett 2004) and/or TAU within clinical psychiatric settings (Janzen 1982; Rose 2015; Whitley 2014; Luhrmann 2001).

[19] Throughout this thesis, I use the term 'social movement' rather than 'revolution' for example, to emphasise the slowness and social character of activism. I refer to 'worldbuilding' as the conscious and 'questioned' articulation of worlds (as oppose to, for example, the "unquestioned, practical, historically conditioned, pre-theoretical, and familiar world of people's everyday lives" (Desjarlais and Throop 2011; 91).

of building different worlds. I challenge the idea stemming from the cognition-related disciplines that healing involves an individual's trajectory towards 'recovery'. I demonstrate how healing is not a finite or progressive state, but a fluctuating and relational process which resists definition. In the fourth section I explore in detail one of the most central aspects of activists' approach to healing: 'mutuality'. I discuss the literature on care and kinship and conclude that mutuality is a useful way of describing the dispersed aspects of support activists offer each other, as well as activists' comprehensive philosophy of health and wellbeing, and the broad range of practices that constitute activist sociality. In doing so, I highlight how mutuality is fraught with conflict and is sometimes forged between unknown persons, thus expanding on conventional notions of 'care' and 'kinship'.

VI (ii) Setting the scene: situating 'mental illness' socially

In this section, I situate the practice of psychiatry and its influence on understandings of mental distress in the UK. I present cross-cultural critical medical anthropological studies (i.e., Kleinman 1988; Locke and Vinh-Kim 2010) that destabilise psychiatric knowledge, examining how social and political conditions impact mental health. Most pertinent to this thesis are studies which examine the conditions of and relationship between socioeconomic pressures, relational failures and mental health. The anthropological literature on the social underpinnings of distress holds that distress is not an asocial process. This literature sheds light on activists' experiences, as discussed in chapter 3.[20] I also draw on this body of work to make sense of how distress is perceived *by* activists. Like anthropologists, activists engage significantly with social approaches wherein distress is perceived as relational and inseparable from socioeconomic and environmental factors. Ethnographies on mental distress highlight how particular phenomena, such as structural violence (Farmer 2004) inequality and lack of access to money and security (Han 2012), high quality food, stable accommodation and the like, exacerbate distress (see also Baer 1982; Singer 2006). I also discuss the concept of social defeat. However, I argue that it is not enough to understand activists' experiences through these lenses and demonstrate that the notions of structural violence and social defeat are often deployed in

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[20] Patient experiences of clinical encounters are not a primary focus of this thesis, as they are extensively covered in anthropological studies and elsewhere (e.g., Taussig 1980; Estroff 1981; Jenkins 1988; Luhrmann 2000; Lester 2014; Myers 2015). Rather, chapter 3 documents how sociality between interlocutors and professionals is intertwined with clinical procedures, to help paint a picture of what activists experience as 'TAU'.

a deterministic manner, such that the complex negotiations which occur between actors and systems are over simplified.

Psychiatric and biomedical approaches to mental illness

Mental-health models, approaches and services in Britain are complex and infused with a multiplicity of theories. However, research on health services and in critical social work makes clear that the influence of psychiatry is proliferating in Britain and now shapes the thinking and design underpinning much, or most, mental-health provision (see also chapter 2).[21] Psychiatry is dominated, in turn, by the biomedical model of mental illness.[22] Many anthropologists have demonstrated that the biomedical paradigm (and its subdisciplines such as psychiatry) is not an identifiable entity in itself (e.g. Hsu 2002; Pickersgill 2012; Callard 2014); nor is it immutable across different sites of healthcare (Chase 2018). Rather, biomedicine is formulated intersubjectively—not as a distinct category, nor an individual experience, but as an assemblage of interacting elements; systems, reactions, feelings and experiences. However, whatever shape or form it takes, activists conceive of biomedicine as a homogenous (and homogenising) force. [23] Moreover, they see this force as having negative connotations for mental health. They worry that it emphasises individual pathology, denying the social and economic causes of mental illness.

Activists' concerns about the biomedical model deployed in psychiatry centre on the psychiatric proposition that illness lies within the physically bounded body, which acts as the receptacle of the mind (Lock 1996). Thus, in psychiatry, biological explanations of distress are favoured over social, individual or relational influences, such as "interpersonal dynamics, experiences or an individual's search for meaning" (Armstrong 2016; 206). Accordingly, accounts of psychosis and other forms of mental illness centre on the brain, rather than environmental factors. In the psychiatric view, mental illness is often

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[21] Luhrmann's (2000) work in particular has also shown how psychiatry has come to dominate in the USA. In Britain, due to austerity and the Covid-19 pandemic, services are stretched. Despite British Government policy rhetoric giving mental health a high priority (DH 2017; see also chapter 2), the NHS is under inordinate pressure due to an exponential rise in both diagnoses (Mental Health Foundation 2017) and treatment regimens (Rapley et al 2011).

[22] So much so that Bemme (2016) coined the term the 'psy'ences to describe psychology, psychiatry, and psychotherapy.

[23] This idea is explored further in section 1.1 where I introduce the concept of the shadow of biomedicine. Additionally, in chapters 2 and 3, I demonstrate how the psychiatric paradigm shapes approaches to mental healthcare delivery and how the shadow of biomedicine, in turn, impacts interlocutors' everyday lives.

considered to be the result of chemical imbalances in the brain (excessive or deficient neurotransmitters for example) causing dysfunction (c.f. France et al. 2007). These imbalances are considered either inherent or a response to external factors; either way, 'illness' is primarily viewed in terms of its chemical manifestation, with mental 'disorders' identified mainly through the presentation of symptoms that match a set of diagnostic criteria.[24] Treatment thus focusses on altering the individual's mind/body functioning through psychotropic drugs such as Selective Serotonin Reuptake Inhibitors (SSRIs) (common antidepressants), and usually entails symptom elimination (Whitley 2014) in ways that are targeted, measurable and quantifiable.

Other significant models operating within the NHS, including systems of psychotherapeutic (or psychoanalytic) knowledge, seek to address problems that extend beyond the 'brain' as a functional organ. However, as Calabrese et al. argue, these paradigms still contain "tacit cultural commitments (e.g. to individualism, rationalism) - including individualist emphasis on intrapsychic causal explanations of distress and…the assumption that autonomy is the ultimate goal of development" (Calabrese et al. 2011; 339). These approaches focus primarily on an individual's cognitive capacities, as in their facility for introspection and self-reporting; thus, treatments prioritise the transformation of a person's behaviour through the re-ordering of thoughts as well as cognitive and emotional processes (Boyes 2008).

Anthropologists of psychiatry and psychotherapy have challenged psychiatric and biomedical models, their views often mirroring those of mental-health activists. They critique explanations of mental illness as something biological, inherent and inevitable in an individual's psyche (Dahlberg 2009) and the tendency to reflect Western notions of the self as a fixed, impermeable and autonomous unit. For example, Bellah (1985) argues that the category of 'the individual' (as reflected throughout research) is awarded an 'ontologically stable status'. Stressing the importance of extending beyond individual cognition, anthropologists have conceptualised the impact of social life *on* mental health in different ways.[25] For example, instead of conceptualising mental illness as a 'disease'

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[24] See the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) 2013.

[25] Whereas Durkheim (1912) Malinowski (1927) and others initially sought to separate the social and 'psy' disciplines- there is of course great variation in 'how much' causality is attributed to social, biological or other factors within anthropology; with some arguing for approaches such as the 'biopsychosocial' (and other) models (i.e., Strauss et al. 2019) of mental illness. More recently, Ingold (2000) for example, has argued for better symbiosis between biophysical and sociocultural understandings of illness which is beyond the scope of this thesis. I do not grant a priori status to social

it is often framed in terms of 'social suffering' (Kleinman 1997). Kleinman describes suffering as a 'transpersonal experience,' combined with "the embodiment of collective memory" (1997; 317), in which the social imaginary permeates the body. Equally, Csordas highlights how the body is "not an object to be studied in relation to culture but is to be considered as the subject *of* culture, or in other words, the existential ground of culture" (Csordas 1990: 5). These earlier anthropological works troubled the distinctions between individual/society, self/other and body/mind, showing that 'the social' is not distinct from other domains.

Critical medical anthropology in particular has engaged with broader political economic and structural determinants of health, more recently using the lens of social justice.[26] Indeed, it is the contention of Biehl, Kleinman and Good that all studies of health and healthcare require examination of the "wider macro forces underpinning illness and distress" (2009: 5). Critical medical anthropology makes an important contribution to understanding how mental health is affected by the social environment in which actors live. Biehl and Locke for example map the 'social side effects', such as 'feelings of failure', arising from the unregulated encroachment of new medical technologies (including pharmaceuticals) among populations living in impoverished urban settings (Biehl and Locke 2010; 318). Similarly, Han (2012) documents how the state impacts the health of people in a low-income neighbourhood in Chile through programmes focused on poverty, mental health, and human rights.[27] Works such as these have informed my understanding of how mental healthcare is perceived and experienced by activists. Drawing from the anthropological understanding that mental health is at least partly socially constructed, my thesis addresses important gaps in anthropological knowledge arising from the many recent changes in the therapeutic field and the wider political and institutional context in the UK.[28] I contribute to this literature by highlighting how structural barriers for those classified as mentally ill impinge on interlocutors' mobility and ability to plan for the future (chapter 6). Further, I demonstrate the detrimental phenomenological and affective impact of state support in the form of diagnosis-dependent benefits on activists (chapter 3).

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explanations of distress; however, this chapter focusses on those studies which are primarily social in focus.

[26] Social justice is a way of conducting anthropology for the specific purposes of instigating social change. It can mean incorporating particular lenses into your analysis, such as decolonisation. For further information see (Jacobs 2014; Greenberg 2018).

[27] The state' is a shorthand for a complex governing body. Jupp defines the 'welfare' state as "a diversity of practices, spaces and relationalities" (2022; 15).

[28] For example, the encroachment of Government programmes such as Universal Credit and 'Fit to Work'.

The diagnosis and treatment of mental 'illness', in itself, often produces adverse effects on a person's social life by limiting possibilities for social connection, potentially leading to stigmatisation, social alienation and isolation.[29] Although I do not directly examine the impact of stigma arising from diagnoses and treatment (which has been extensively dealt with elsewhere),[30] it is deeply embedded in the lives and stories of my interlocutors. My ethnography crucially elucidates how treatments change people's views of themselves and their illness (Kohrt et al, 2016: 397). Studies that demonstrate the social impact and experience of being 'mentally ill' are therefore highly pertinent to my thesis. Taussig (1980), for example, has drawn attention to the misalignment of patient and professional 'realities' and how these are tied to social relations (in interactions with clinicians, or other professional interactions). Specifically, he outlines how the lived experience of illness has been denied by health professionals, with the effect of alienating patients during treatment. He examined the reification (or what he calls 'thingification') of disease in the interactions between clinicians and patients in a North American teaching hospital. The term 'reification' is used to indicate how disease is rendered a matter of purely bio-physiological processes by institutional and professional context, thereby mystifying the 'social language' of the body (or what today might be called 'the patient experience'). The effect is such that illness is 'concealed within the realm of biological signs' that are only interpretable by 'professional experts' (1980; 5). Thus, being unable to use her own language to interpret it, the patient becomes alienated and disempowered by her condition, as much as she does from the relations with the professionals involved in its production. The patient experience is delegitimised, and the patient denied support. This sense of alienation and patients' estrangement from treatment processes resonates closely with my interlocutors' anxieties concerning the denial of their experiences and 'silencing of their voices' (see chapter 3).

Structural violence (sometimes termed structural abandonment)—a key concept in medical anthropology—has been used to describe the adverse impacts of the institutions

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[29] This perspective is well documented. See for example (WHO 1979; Hacking 2001; Thornicroft 2006; Fuentes 2020; Gagné 2020; Jenkins et al. 2020). Researchers of illness in general highlight the ways in which the illness experience can disrupt a person's expectations, lives and relationships; these circumstances often being framed as an interruption of social life and of personal biographies. Bury (1982) classically called this biographical 'disruption'.

[30] See c.f. (Yang et al. 1982; Weiss et al. 2001; Jenkins 2009; Jenkins and Carpenter-Song 2008; Myers 2016).

and structures of the state on its subjects.[31] First developed by Galtung, it refers to forms of violence that come about "with no single identifiable actor" (1969; 170). For Farmer, structural violence is "the social machinery of oppression which constructs the agency of victims" (2004; 307). It alludes to social and institutional arrangements in which power harms individuals or populations without there being a clear perpetrator, as in the recurrent marginalisation of persons (or groups) through gender, economic, and racial disparities, or the denial or cessation of access to basic services like healthcare and education. Farmer (2004) also employs the term structural violence to highlight the kinds of conditions that create social defeat. I find this framing particularly useful for understanding the tension my interlocutors experience in their efforts to apply their agency in the face of overwhelmingly detrimental structural conditions—many of which are entirely beyond their control. In particular, I use the term to illuminate the 'barriers' interlocutors confront when trying to access, or forge meaningful pathways through, mental healthcare. It points to the specific relationships between those systems, bureaucratic or otherwise, which impede actors' progress and undermine their ability to heal from mental distress. It therefore key to understanding activists' affective and political responses to healthcare, since many feel abandoned, or even pursued, by the state. In the same vein, Povinelli explains how economies of abandonment "allow the killing of all social projects that do not produce market forms of life, to be justified on the basis of a distinction between societies of freedom and those of constraint, and the security risk of allowing the latter to gain a footing in the former" (Povinelli 2011; 29).

Activists frequently convey the sense that they feel as though they pose a 'security risk' to society, much as Povinelli describes. For example, one activist explained how hospitals are designed architecturally to make you feel watched at all times (see chapter 4). Activists also experience fatigue and sickness associated with their struggle to 'be the change' they wish to see (chapter 5), these emotional responses reflecting research by others on how austerity wears subjects down in 'repetitive ways' (Jupp 2019; non-paginated). In describing one hospital in which patients were abandoned by their families, Biehl (2013) advanced the notion of 'zones of social abandonment'. This refers to domestic or public spaces in which 'disordered' subjects are confined, whether to dwell or to be left to die (*ibid*; 132). Marrow and Luhrmann suggest that in these zones, "social marginalisation takes place by stripping away the subject's efficacy in social communication" (2012; 493).

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[31] This concept was first coined by Johan Galtung in his article (1969) "Violence, Peace, and Peace Research". *Journal of Peace Research* 6:167–191.

In section VI (iii), I describe the stripping away of activists' ability to communicate in particular therapeutic spaces, a circumstance addressed in activist literature on epistemic and hermeneutical injustice (see also, chapters 3 and 4).[32]

Luhrmann (2007) is another medical anthropologist who explores the connection between structural conditions and agency through her work on the relationship between structural violence and social suffering. Luhrmann's attention to the political-economic circumstances of people diagnosed with schizophrenia in the USA echoes the kind of structural barriers described by my interlocutors as impinging on their lives. Exploring how schizophrenics are 'not fully accepted by society' (Patterson 1982), Luhrmann argues that those diagnosed as mentally ill are worn down by neglect and healthcare failures, so that they experience constant disaster and abjection in their social encounters. She calls this phenomenon 'social defeat'. Social defeat rests on the notion that the subjective experience of being 'ill' is impacted by structures of power and social conditions, this interaction, she argues, affecting the course, outcome and even the origin of illnesses such as schizophrenia. In this way, Luhrmann shows how social life can be *rendered* through the body - troubling the separation between social and biological approaches to understanding distress.[33]

While the notion of structural violence is useful, it can be problematic if looked at in isolation from peoples' full social, economic and political worlds. Valid criticisms of the concept include that it can be ill-defined, functionalist, totalising and overly deterministic (e.g., see Bourgeois & Scheper-Hughes, 2004). Although I do not mean to imply that Farmer and Luhrmann are using structural violence in a totalising way, I concur with these views, and in chapter 3, argue that it is not enough to understand patients' interactions with mental healthcare as instances of structural violence, social defeat, or even as everyday acts of resistance. These frameworks paint a one-sided picture of activists' experiences of diagnosis and struggles with healthcare and social-welfare services. The risk is that, as a consequence, activists' experiences will be understood as less complex and more polarised than they are. In chapters 3 and 6, I show that interlocutors are aware of and respond intentionally to social defeat in their activism, so that 'failure' does not obstruct but forms an intrinsic part of their political activities. Further, I detail the

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[32] In chapter 4 I examine how activists reclaim 'zones of abandonment' in the city of London, making their own therapeutic spaces in quiet and desolate parts of the city.

[33] The concept of social defeat is particularly poignant in light of my findings in chapters 3 and 6 – which explore how activists experience constant uncertainty and disappointment, which in turn, have physical and affective consequences— 'making' people sick.

negotiations between activists and health professionals as embodying a 'push and pull' dynamic that is quite different from the picture of 'powerlessness and passivity' (Laws 2009; 1830) portrayed in several studies of structural violence (Foucault 2001; Masson 1993; Szasz 1974). As Jenkins and Carpenter-Song show, people with mental illness are often "strategically skilled at responding to social assaults on their personhood" (2008; 381), exercising "strategies of resistance against the threat of stigma-related social defeat" (Wright 2012; 660). Rhodes' (2004) study is also pertinent to this argument, as her ethnography of a maximum-security prison in the USA reveals how expectations of manipulation characterise interactions between prison guards and prisoners in which "running a game" and "knowing the game" become an organising principle.

Conditions of violence, abandonment and defeat thus create motivations for resistance, with activists responding in a manner that can cultivate hope and endurance. I conceptualise this kind of interaction between actors and the structural constraints bearing down on their lives as a form of 'healing otherwise' (see section 2). Another relevant critique of the concept of structural violence is Varley and Varmer's reminder that violence does not just happen 'outside' or 'alongside' medicine, but *within* it—as structural determinants of health such as racial injustice are "capable of producing as [much as] resolving disparities and inequities" (Varley and Varma 2021; 144).[34] In other words, as I maintain in chapters 2 and 3, structural violence manifests in professional discourse around mistrust of patients, this discourse greatly disadvantaging those seeking treatment. In line with this argument, in chapters 5 and 6 I assert that healing is not always a wholly 'positive' or generative experience, particularly when activists' endeavours to heal 'otherwise' are constricted by enforced interactions with the services that perpetuate said violence. Recently, Cubellis (2019) has argued for a more nuanced understanding of the impact of violence during attempts to heal, which she terms 'wounding'. She suggests that wounding happens when a person who draws from their own experience of harm to support others with similar experiences is unable to realise their potential due to structural constraints, including crises in welfare.[35]

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[34] The concept of clinical iatrogenesis commonly applies to harm done to patients accidentally, as a by-product of medicine, whereas Varley and Varmer argue that iatrogenesis in medicine in India and Pakistan-controlled Kashmir, is in fact deliberate and systemic, such as that which comes from racial inequality, sexism, ableism and the like. They connect medical iatrogenesis to increased risk of death. See also Ecks (2021).

[35] I explore 'wounding' in chapter 5, to examine the mutual hurt which takes place between activists.

Having examined some of the concepts I use in the thesis to interpret how activists' suffering is shaped by structural violence, I draw now on literature that explores the generative impact on individuals of social approaches to mental distress—this literature having informed my framing of what constitutes healing (discussed in section 3). For example, research on self-help groups and therapeutic communities (Janzen 1982; Brown 2002; Calabrese 2008; Rimer 2014) indicates that illness can result in social regeneration rather than isolation or disruption. Such work is useful in demonstrating the different ways in which subjectivities and identities shaped by distress, illness and treatment can facilitate belonging and enable the emergence of a sense of community.[36] Bradley, for example, has written on the concept of 'biosolidarity', a term she has adapted from Rabinow's (1996) biosociality, to describe how people with shared biological conditions come together to form social networks (primarily through Facebook) based around activism and advocacy (2020; 1).[37] Ethnographic accounts such as Bradley's demonstrate how particular elements of the illness experience can be fostered among people to enhance sociality. In chapters 4, 5 and 6 in particular I focus on ideas and enactments of the 'good life' (Robbins 2013; Laidlaw 2014), addressing ethnographic accounts of personal and collective transformation through sociality.

The shadow of biomedicine

In chapters 2 and 3 I demonstrate how NHS and DWP rules and regulations cause interlocutors unnecessary anxiety and stress. However, I seek to move *beyond* a Foucauldian analysis of mental health and welfare praxis, which is concerned primarily with how healthcare affects different subjects and functions under different forms of governmentality and control (see e.g., Foucault 1965; 1973; Rose 1989; 1998). For activists, the lived experience of 'biomedicine' is not as easily distinguishable from

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[36] Anthropological studies have emphasised the importance for healing of both friendships and relationships with healing figures (see, for example, Szasz 1992; Berkman 1995; Makela 1996; Berkman et al. 2000; Warner 2008; Lester 2013). Peer support literature usefully highlights how people who experience the same or similar conditions aim to disrupt the patient/healer dyad and asymmetrical power dynamics typifying clinical relationships through mutual support (see e.g., Blackman 2007; Noorani 2016)

[37] Intentional therapeutic sociality has been explored in the context of biomedical citizenship (see for example Adams 2013; Whyte et al. 2013; Nguyen 2008) and clinical healthcare settings, with much of the anthropological literature on mental health in Euromerican contexts focusing on the patient/healer dyad in psychiatric treatment (e.g. Kleinman, Eisenberg and Good 1978; Kleinman 1981; Estroff 1981; Torrey 1986; Mattingly 1994; Desjarlais 1997; Luhrmann 2001; Jenkins and Barrett 2003; Rhodes 2004; Brodwin 2013).There are very few studies of groups that operate outside biomedicine, services or the care sector.

'alternative' approaches to, or spaces of medicine as some anthropologists have implied (i.e., Lock & Gordon 1988; Canguilhem 1989; Clarke et al. 2010; Harvey 2008; Davis 2012; Yates-Doerr 2012; Cook 2016). Moreover, as I argue in chapter 4, while interlocutors may describe biomedicine as a monolithic force, their interactions with the biomedical model are negotiated dialogically in clinical settings.[38]

In the context of my research, the phrase 'shadow of biomedicine' evokes the blurred lines between both biomedical and other spaces as well as the present and the past. Shadows always accompany their subjects but are not necessarily coherent and do not constitute their physical person. The shadow of biomedicine manifests in interlocutors' histories, as well as in their narratives, relationships and spatial practices (see chapter 4), constantly lurking at the edge of their lives. For interlocutors, there are no 'de-medicalised' spaces (as Yates-Doerr & Carney 2016 might contend), only worlds that are *becoming* so. As Peluso describes it, interlocutors experience an 'afterlife' of biomedicine (pers. comm., 2020).[39] I refer to the 'shadow of biomedicine' to reflect the intangibility and porousness of its presence in activists' lives and to avoid the reification of biomedicine, since each individual's experience of it is distinct. Thus, biomedicine and the mark it has left behind is an absent presence (Gilsenan 1996; 59) throughout this thesis.

VI (iii) A case of hermeneutical injustice? From 'mental illness' to 'distress'

My understanding of mental distress is informed by activist debates around hermeneutical/epistemic injustice. It concurs with the argument advanced by Kleinman and colleagues (1978) that different explanatory models of illness used by professionals apply different notions of the causes, symptoms and treatment of particular diseases, and that these distinctions in turn shape patients' responses and outcomes to treatment. These authors show that patients' understandings of distress can vary widely with age, gender, education, social class, experience, as well as cultural and religious influences, in contrast to professionals, and that their views are often in conflict with professional

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[38] Anthropologists looking at resistance have also criticised the polarised way in which structure and resistance are often pitted against each other (c.f. Laidlaw 2013).

[39] Similar to my conceptualisation of the shadow, Das (2006: 76) uses the term 'poisonous knowledge' in her study of conflict between Pakistan and India to describe how events of the past interrupt the present through memory and experience.

models, this frequently hindering their recovery from illness.[40] This conceptualisation is extremely useful in highlighting one of the primary reasons behind interlocutors' aversion to terminology such as 'mental illness'. However, like others (e.g., Scheper-Hughes 1990) I find that the notion of 'explanatory model' rather oversimplifies the variation in individuals' understandings of distress. It implies a specific, coherent, 'model', when it is more likely that understandings of health resemble "a patchwork fabric, made of densely tangled yarns" (Wierciński 2021; 74).[41] The idea of tangled yarns more closely mirrors the blurriness of interlocutor's relationship with biomedicine and their understandings of distress.

Recent work in mental-health activism makes clear that when patients' explanations conflict with clinicians' models, this can hinder their recovery and exacerbate their distress, especially where the psychiatric model prevails. Scholars and activists use the term 'hermeneutical injustice' (coined by Fricker 2007) to describe this circumstance. According to Fricker, hermeneutical injustice is when someone has "a significant area of their social experience obscured from understanding owing to prejudicial flaws in shared resources for social interpretation" (2007; 1). For example, referring to 'explanatory models' rather than describing the complexity of distress, prevents effective communication with and personal expression by individuals with mental-health diagnoses.[42] Often, the diagnostic categories of health professionals have no meaning for patients, such that they feel highly constrained when describing their mental distress, this effectively constituting a denial of their lived experience.[43] Applied more broadly, hermeneutical injustice can point to "gaps in the social imaginary that prevent service reform" (Armstrong 2016). At its worst, it is suggested that hermeneutical injustice undermines activists' sense of 'ontological security'; or, in other words, their sense of belonging, or feeling comfortable, in their world (Saunders 1986).

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[40] The contention by Kleinman and colleagues that explanatory models can contradict helps to explain why my interlocutors reject terms such as 'mental illness'.

[41] Kleinman himself later changed his view on the concept of explanatory models, purporting that he was "less impressed by systematic connections and more by differences, absences, gaps, contradictions, and uncertainties" (1995; 7-8).

[42] Here I am referring to specific categories used to depict a person's experience, such as 'depression', 'anxiety, 'low mood' or other terms which are standardised, medically accepted ways of describing a person's condition.

[43] Writing from the perspective of a psychiatric survivor, Daniels puts it more strongly by arguing that "the social valorisation of doctors as key-holders of reality, conformity, and morality creates an abyss of distance between patient and doctor which seems to swallow up any evidence against [patients'] right to this position of power" (Daniels 2021; non-paginated).

The social significance of terminology is and has always been, of vital importance to mental-health activists. Self-determination and autonomous knowledge production are highly valued, and language has strong political and emotional resonance. Arguing for the legitimacy of alternative conceptualisations of mental health is a key focus of activism and activist terminology is often designed explicitly to reduce the stigmatising effects of terms in common usage in medical circles. Thus, activists generally avoid clinical and diagnostic language.[44] For example, the term 'mental illness', as employed in the medical vernacular, is deemed both offensive and inaccurate. Activists prefer terms such as 'distress' or 'acute stress' since these highlight the negative aspects of certain mental states without implying any pathology. 'Distress' is a conscious departure from conventional psychiatric notions of mental illness focusing on biological malfunctioning and the requirement that patients be cured. It covers a diffuse range of psychological, social and emotional experiences and makes clear that managing distress is an 'everyday', socially oriented and embedded, or relational, practice. It follows that what psychologists and psychiatrists might refer to as 'hallucinations', 'delusions' and 'visions' are perceived by activists as neither abnormal nor symptoms of illness, but simply other (albeit exceptional) dimensions of everyday human experience. Certainly, activists do experience distress as uncomfortable and difficult, but they also perceive it to be a normal response to what they regard as an 'insane world'.[45] Moreover, the term 'distress' is intended to be comprehensive and to reflect the complexity of activists' experiences and states. It covers all of the mental challenges experienced by my interlocutors, including those— 'schizophrenia', 'bipolar disorder' and the like—that are subject to biomedical diagnoses. Since my aim in this thesis is to understand activists' perspectives and experiences I use the term mental distress, rather than mental illness, throughout. The term acknowledges the causality in environments, intersubjective relations and that distress is not simply cognitive, but also embodied.

In this section I have highlighted how the social constituents of mental distress are considered significant by both activists and anthropologists. I have also pointed to the limits of certain conceptualisations, particularly structural violence and social defeat. In the following section I explore various theoretical explanations around collective responses to conditions of structural violence, abandonment and defeat.

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[44] Andy once cautioned me for calling a mental-health professional a 'doctor', arguing that such a term "might imply they help people".

[45] This is taken from a quote often paraphrased by activists, originally by the radical psychiatrist R.D. Laing (1972), a key advocate of the social causes of mental distress.

VI (iv) Worldbuilding, otherwise and prefigurative politics

I turn now to reflect on interlocutors' collective activism and ways of organising in the context of socio-political struggle. I draw mainly on literatures that focus on social movements and ways of creating life differently, since these evidence the kind of politics that typically emerge in such circumstances. Questions such as 'how' and 'why' people organise, 'what moves them' to take risks and make sacrifices and 'what can we learn' about how to construct better worlds, have been consistently asked throughout such scholarship. The consensus is that social movements provide the conditions for people to re-construct their relationships and re-configure their lives; thereby "altering the ways in which people conceptualise and experience the world" (Cherstich and Holbraad 2020; 155) and "setting the conditions of authoring" (Escobar 2004: 258). In other words, social movements are spaces in which actors depart from the status quo and enact politics with transformative potential, bringing future-oriented ways of being into the present. Particularly relevant to mental-health activism (as outlined in chapters 3 and 6), are studies of social movements that arise in response to crisis and struggle (see e.g., Mittermaier 2012; L' Estoile 2014; Rodima-Taylor and Bahre 2014; Narotzky and Besnier 2014). I am concerned primarily with 'modes of politics which operate outside conventional public or political spheres' (Jupp 2022; 32). Understanding what motivates social movements is one thing (see for example Rutten 2003; Brodkin 2004; Tarrow 2011; Thomassen 2012), but less is known about how relationships are sustained amidst struggle and what *really matters* to activists over time (Kleinman 2012). These questions are especially relevant for mental-health activism in London, which, as I show, has endured for many years despite being based on very informal, loose networks. London's mental-health activist movement has a life of its own well beyond its constituent events and activities.

During fieldwork I encountered many situations in which healing, and politics were implicitly enmeshed, seen almost as indistinct. However, there were very few instances in which mental-health activists articulated this relationship clearly, as well as very little mention of concrete political objectives. Due to this holistic approach and the entangled character of the healing and political components, I examine mental-health activism as a form of worldbuilding (Zigon 2014a; 2017a; 2017b; 2018). I also engage with related notions of 'prefigurative' and 'otherwise' politics in order to shed light on the seemingly shapeless political practices of activists.

Worldbuilding

First coined by Zigon (2014a), the concept of worldbuilding is used to describe how actors articulate and realise 'alternative social and political imaginaries' (Zigon 2017a; non-paginated). The imaginaries I refer to in this thesis are about forms of healing and political structures that offer an alternative to Treatment as Usual (TAU) in mental healthcare and broader concerns relating to capitalist society such as social disconnectedness and the marketisation of care.[46] Importantly, worlds are not 'containers of culture', nor are they "backgrounds in which certain practices and cosmologies make sense; rather, they emerge from everyday conditions and situations" (Zigon 2018; 152). In the case of activists, worldbuilding involves their spatial and relational practices, their ways of being and forms of political engagement. For Zigon, worldbuilding is primarily about asking the question 'what is it between us?'; referring to the space 'between' one person and another where singularity and relationality meet (or what he calls fidelity and alterity) (2014b).[47] Zigon's question frames worldbuilding in terms of relational ethics. Relational ethics, in his view, extends to how people open and extend possibilities for others.

In his ethnography of drug-user 'agonists'[48] (mainly in the USA) who organise against the global 'war' on heroin and crack cocaine, Zigon details how actors engage in political processes that seek to allow new possibilities for 'being-with' others, thereby laying the onto-ethical grounds for new worlds (Zigon 2009; 13). He outlines that, "a politics of worldbuilding begins from the assumption that worlds are built first and foremost through the creative and experimental enactment of such relationalities of being-with" (2017a; non-paginated). Zigon argues that phenomenology has been misconstrued by many anthropologists, insofar as it is not just concerned with the lived experience of people in terms of their subjectivity but is also an "analytic method for the study of sociality" (Zigon 2009; 286). It does and can include political-economic approaches, as I show in this thesis. "Phenomenology is not concerned with describing the experience of individuals, but rather with the description of processes of interrelationships" (Zigon and Throop 2021; 6). In Zigon's view, worldbuilding concerns how actors attune to others. He contends that being

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[46] I use 'capitalism' in the ways in which interlocutors referred to it. For the most part, capitalism serves as a shorthand for particular conditions.

[47] Zigon's 'in between' evokes the Samoan indigenous reference of 'teu le va,' which means "to value, nurture, and care for (teu) the secular/sacred and social/spiritual spaces" *in between* people (va) and in all relationships (Anae 2019; 2).

[48] The term 'agonist' is used by Zigon instead of 'activist' to highlight the "agonistic nature of the political struggle of those fighting against the drug war" (Zigon 2015; 522). It is derived from agonism – a socio-political term that emphasises the positive aspects of conflict.

relational is derived affectively; it is the capacity for being intersubjectively social. As Zigon explains:

> a politics of worldbuilding as beginning from a situation, and proceeding to open possibilities for what worlds can become and how existents can come to dwell (that is, be-with-openly) within them by means of altering the relationalities between those existents...[…]… a politics of worldbuilding begins from the assumption that worlds are built first and foremost through the creative and experimental enactment of such relationalities of being-with (2017b; non-paginated)

Zigon's formulation is influenced by the work of phenomenologist Heidegger, who highlights the significance of people's 'lived relationships' with spaces. Heidegger (1951) interprets 'dwelling' as the accommodation of people with their surroundings; conveying far more than a mere physical location but signifying how people *belong* in spaces. To put it more precisely, "Where one dwells is where one is at home, where one has a place" (Wheeler 2011; non-paginated). In chapters 4 and 5, I explore how activists express intersubjectivity through space-making and acts of mutuality that entail a deep understanding of and compassion for others. I show that this is often articulated by letting others be, rather than intervening to alleviate their distress.

Zigon also discusses the presence of 'disclosive freedom' in agonist networks.[49] This kind of freedom, he argues, is not sovereign – "it is not about the freedom of the individual to master his or her own will" (2018; 103). Agonists are encouraged to participate in key decisions whatever their state of mind, even when high on drugs. Zigon observed that agonists often arrive late at meetings and seemed distracted, unable to concentrate. Consequently, the process of decision-making is extremely slow and sometimes entirely ineffectual. At first, Zigon wondered why agonist groups do not formulate clear rules around participation in meetings, for efficiency, fairness and the good of the movement more generally. However, he concluded that to expect meetings to be organised around formal systems and structures is to misunderstand what they are about,

> These meetings… were *clearings* in which freedom is not a property of individual human beings but rather *an attuned atmosphere that emerges through the mutuality of letting each other be*, from which becoming any kind of being is a possibility for any of those there (2018; 119, *my emphasis*).

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[49] Zigon's ethnography is assemblic; spanning multiple countries, including the USA and Indonesia. I am most interested in the work he conducted in Vancouver and Copenhagen.

'Attunement' and 'disclosive freedom' (Zigon 2018) are useful terms for conceptualising the dynamics of activists' relational practices. In chapters 4 and 5 I show that healing worlds are social and depend on actors creating therapeutic environments through practices that enfold between people and spaces. I advance Zigon's concept of attunement by examining activists' everyday listening practices as a kind of embodied 'training of attention' (Grasseni 2010). Activists pick up social cues about how to listen from one another, and occasionally from classes and workshops. Yet listening is not a formal practice, but an intersubjective engagement that becomes consolidated over time.

Prefigurative politics[50]

The notion of prefiguration has become increasing popular in recent years. It reframes understandings of activism in such a way as to acknowledge that the informal and sometimes seemingly amorphous processes it involves are indeed political in nature— even when there is no obvious outcome or evidence of progress. Prefigurative politics incorporate local, community, care-based activism and in Jupp's view, should not be regarded as "secondary to 'proper activism' involving explicit ideologies, visions and programmes of political change" (2022; 32).[51] Prefigurative politics refers to a range of social experiments and ways of being that critique the status quo whilst also offering alternatives (Cornish et al. 2016). The premise of prefigurative politics is that actors both imagine and produce a society that is significantly different from the existing 'model' (Graeber 2009). Thus, Graeber defines prefigurative politics as "the mode of organisation and tactics undertaken which reflects the future society being sought by the group" (*ibid*; 11). One important aspect of this formulation is the refusal to engage with, or the avoidance of, pre-existing political structures or systems. In other words, prefigurative politics entails an intentional move away from conventional democratic structures, such as political parties, and involves both "detachment from any identifiable political ideology", and autonomy from hegemonic political institutions (Giddens 1994; 46). As I show throughout this thesis, interlocutors reject not only the biomedical model and formal modes

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[50] Much of this section has formed part of the paper, Howard and Pratt-Boyden (2013) - the included extracts of which I was the sole author.

[51] In her study of local activism in the UK, Jupp notes; "Certainly very few [local activists] would have called themselves 'activists', or even have described themselves as doing anything political. Yet, their actions may still be enacting or bringing into being 'new ways of being in the world' at whatever scale." (Jupp 2022; 32)

of mental-health treatment but also conventional forms of political citizenship (i.e., such as adhering to predetermined goals). [52] Manifestos, voting, etc. undermine the indeterminacy activists seek. Thus, the concept of prefiguration brings into focus the ways activists build worlds and is also vital to understanding how activists maintain and enact (inter)subjectivity.[53]

One of the distinguishing features of prefigurative politics is actors' relationship with temporality. Scholarly debates around prefiguration centre on whether or not the concept implies a projection into the future. For example, although not employing the concept of prefigurative politics, Crossley speaks of social movements as 'working utopias', which, in his view, generate "new forms of knowledge and social relationships" (1999; 829-830). These utopias challenge existing social norms and values by producing "new ideals for living" (ibid; 810). Likewise, Deleuze and Guattari envision the potential of such movements to "create new possibilities […] invent new forms of existence, articulate alternative futures […] and create zones against dominating power relations" (Deleuze and Guattari 1987; 33). As Graeber observes, you are creating the sort of society you want to have, but in miniature (2011; 281). As I show, the kind of pre-figuration undertaken by activists is less about working toward a *particular* future, and more about maintaining indeterminacy – keeping 'the future' unspecified, much like trade unionists in Buenos Aires, as Lazar explains; "'The future' is kept indeterminate. Process is the issue; democratic discussion itself is what is most important" (Lazar 2012; 95). Prefiguration broadens the debate about what politics actually *is*, expanding its scope beyond formal party structures, voting procedures, and campaigns and events, such as protests or marches, to incorporate far more nebulous political processes of the kind enacted by mental-health networks in London.

If social movements are spaces where actors construct alternative, indeterminate worlds, phenomenological understandings of 'becoming'—in which subject and world emerge together (Evens 2005; 51-2)—are also of relevance. Stemming from the metaphor of the rhizome, which has "neither beginning nor end, but always a middle from which it grows and which it overspills" (Deleuze and Guattari 1988; 21) the concept of 'becoming' refers to the continuous, in-motion, and 'unfinished' elements of prefigurative politics. The

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[52] Similarly, Jupp traces how studies of citizenship have turned to "models of citizenship based on participation and process, rather than formal legal or political rights" (2019; non-paginated).
[53] For more ethnography exploring prefigurative politics, see (Graeber 2009; 2013, Maeckelbergh 2011; 2012).

concept illustrates how activists enact de-territorialised "motives that become realised *in the process* of pursuit" (Levy 2005; 25, my emphasis). Drawing on Deleuze, Biehl and Locke identify this process as,

> the individual and collective struggles to come to terms with events and intolerable conditions and to shake loose, to whatever degree possible, from determinants and definitions...an existential stage in which life is simply immanent and open to new relations—camaraderie—and trajectories (Biehl and Locke 2010; 317).

Indeed, the kind of politics mental-health activists perform seldom has recognisable, coherent goals or objectives. In fact, interlocutors often resist having to communicate particular goals, as I demonstrate in chapters 4 and 6. I show how, for activists, prefiguring a different world means keeping spaces open and political solutions indeterminate, so as to allow expression of diverse views and actions.

Long and Moore emphasise the transformative nature of this social process, maintaining that "sociality is about *doing* something together, and *becoming* different in the process" (Long and Moore 2012; 171). Thus, in chapters 4, 5 and 6, I show how activists *become different* through relational practices and activities centred on mutuality and politics. Such acts help to bring people into 'being differently', as I highlight in chapter 5.

Alternatives to Prefiguration? 'Otherwise' and Indeterminate politics

Recently, scholars have begun to use the concept of *the otherwise* to refer to "political potentialities *that are still emerging*" (McTighe and Raschig 2019; non-paginated, my emphasis). Drawing on 'critical phenomenological' perspectives, such as those of Heidegger (1971) and Povinelli (2015), 'otherwise politics' is employed to address shortcomings implicit in the concept of prefigurative politics—i.e., that it is even possible for activists to live the change they wish to see given the challenges they contend with. For Zigon, for example, prefigurative political activity is only possible in *certain* conditions. He cites the Occupy protest camps as an example. In his view, camp populations were comprised of Western liberal-minded individuals who came together temporarily, outside the context of their daily lives. In other words, the camps were a kind of blueprint of prefiguration, in that, as relatively privileged members of society, activists were able to separate themselves from their 'real lives'. 'Otherwise politics', Zigon counters, happens

when actors have the possibility of making life different in the context of their *everyday* lives. Agreeing with Zigon, Raschig (2019) identifies political subjects who work with the otherwise as distinct from activists who operate within a frame of prefigurative politics. She argues that whereas prefigurative politics are born out of middle-class social movements, otherwise politics involves creating what you can within *existing social conditions*. Raschig further maintains that acts of otherwise politics are seldom recognised as truly 'political' in nature. To her, otherwise politics is;

> a form of politics that is neither de rigueur nor radical… Arising in overlooked sites and makeshift configurations…that which is otherwise (rather than 'other') maintains a fundamental provisionality that echoes in its conventional usage as 'what might be' in different circumstances, or 'what may happen' if some - thing else does or doesn't (Raschig 2016; 16).

According to Raschig, the 'otherwise' cannot be evaluated by concrete transformations but involves instead "tiny displacements" or "thresholds of activity" (2016; 19) which are not measurable.[54] Her thesis is that political 'potentiality' is distributed unequally across society and is therefore variably accessible (2016; 18). Thus, when populations face overwhelming structural constraints—economic precarity, racism, sexism and/or ableism and the like—it is not appropriate to apply standardised criteria to assess the outcomes of social action. Raschig draws examples from Latina women who engage in activism around the murders of young black men (often their own children) by the Californian police force. She suggests that, as a disadvantaged minority group exposed to an oppressive police system, the women seek to collectively campaign about the entrenched violence and injustice they experience. However, she found it hard to identify concrete outcomes from the women's actions, in large part because the women were not positioned structurally to achieve the kind of political transformation they sought. Therefore, rather than trying to gauge whether or not their movement was a political 'success', Raschig researched how her interlocutors felt about being involved in the process.[55] The women described how engaging in healing circles and standing on street corners holding placards containing the slogan 'enough already' gave them the sense that '*something* is happening'. They felt as

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[54] C.f. (Zigon 2018; 20).
[55] Exploring these differences in political engagement further, Raschig identifies the prevalence of exhaustion among the women as a "somatic condition of contemporary politics" and traces how this 'state of being' brings to light "unjust social configurations rather than individualized failure or apathy" (2016; 22).

though they were part of a process they knew to be 'different', even without being able to articulate what that process might be. Raschig writes, "The women in this poor community may have little clear sense of the future...despite having certain goals on paper, but they know that 'something' is changing" (ibid; 156). She calls this a "hermeneutic giving coherence to the feeling that something – and something important – was happening, where it might otherwise be overlooked or illegible" (ibid; 157). Thus, in a context where public meetings are interpreted by the authorities and community members alike as subversive, simply 'being-with' others in a way that is novel to the women constitutes a form of 'otherwise' politics.[56]

The concept of the 'otherwise' is helpful in understanding those small changes occurring among activists that cannot be identified as embodying a particular future-facing goal. The otherwise emphasises what is already happening in the present rather than what is hoped for in the future, as might be implied by the notion of prefiguration. In this sense, the concept attends well to the ways in which intentions are implicit, unspoken, and figured out as they are lived. The otherwise also reminds us to be cognisant of conditions, such as stigma and poverty, which may place actors in a state of liminality, unable to live out their desired political imaginaries and prevented from achieving political goals.[57] However, I disagree with the argument advanced by Zigon and Raschig that prefigurative politics is isolated from and external to actors' everyday lives. Even though actors exposed to structural violence may have few opportunities to actively 'choose' the world they want to live; I demonstrate in chapters 4 and 6 that prefiguration is indeed feasible in the context of precarity. The ways in which activists enact politics in the face of structural conditions prefigures the worlds and ways of being that they desire; they also enact ways of being which open up possibilities of becoming. Activists come from diverse socio-economic backgrounds, and largely because of their ill-health, many experience poverty and economic insecurity. Some confront barriers to social mobility; repeated bouts of illness and treatment mean that many are unable to achieve aspirations such as completing their education or remaining full-time parents. Yet, actors still prefigure worlds in contexts of struggle and oppression, even without being able to 'fully realise' their political visions. In

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[56] Jupp (2012) makes a similar case for neighbourhood community groups in the UK – arguing that the potentialities of everyday and embodied local activism have been obscured and overlooked. Elsewhere, she also talks of the "hidden benefits" of community centres (such as everyday care) that are "not valued in policy frameworks" (2022; 67).

[57] Koch's (2016) study of residents on English council estates echoes the need for the lived realities of social class to be included in aspirational narratives for "alternative" democratic futures.

fact, I argue that the suspension of political visions is often a purposeful part of building indeterminate worlds. Further, it would be remiss not to note that the concept of prefiguration is often how interlocutors themselves describe their actions; many having been involved in the global Occupy movement which harnessed the discourse of prefiguration, as mentioned previously.

I contend that in the volatile and challenging context of mental-health activism, prefiguring 'other' ways of being also has powerful healing potential. Although activism often on the surface appears to be mostly about systems reform or societal change, it is also deeply concerned with personal change, allowing for both the maintenance of hope and possibility, and transformation and becoming. Some critics of prefigurative politics (see e.g., Krøijer 2020; Zigon 2017b) see distinctions between "feelings of personal empowerment" and 'strategic gains' (Srnicek and Williams 2016; 8). However, my data show that these are not mutually exclusive; personal empowerment is directly connected to strategic gains; the personal, social and structural are deeply entangled. For activists, personal gains are often profoundly political since they have broader social implications.[58] Mental-health activists conduct politics through a diversity of means, not just overt collective action, such as protests, but also individual and often subtle acts of resistance and support in response to everyday hardships--these latter frequently extending outward to the wider activist community. As I demonstrate (primarily in chapter 6), given the many challenges they confront and the frequent disappointments they experience, part of activists' prefiguration is to maintain a state of indeterminacy in their political engagement. Indeterminacy is different from uncertainty, in that it is an intentional suspense of coherence.[59] It is not that activists are caught in a situation of *not knowing* what is going to happen, rather, they take an active stance to keep the outcome of their activities 'open' (and potentially unknown). Thus, in chapters 4, 5 and 6, I show that, rather than working to concrete change objectives, activists 'guard and hold' space for one another. Meetings take place without agendas; deterministic language around mental 'illness' is avoided. And in chapter 6 in particular I examine how interlocutors intentionally adjust their aspirations and expectations in response to things not going to plan. In other words, activists are

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[58] For example, in chapter 6 I document Julie's refusal to let a passer-by take away her 'Arbeit macht frei' sign– this move she regarded as a personal triumph as well having wider social implications for the recognition of the situations of people with mental distress who are forced into work. In her work on community activism, Jupp (2020) similarly argues that storytelling gives value to social centres, and shape to diffuse practices and experiences in a way that can be understood as citizenship.

[59] Sanchez (pers comm 2021) has argued that uncertainty is usually understood as a condition that happens *to* people and is beyond their control.

working toward *other* worlds, rather than *a particular* world. I show that maintaining indeterminacy takes a great deal of effort, including careful planning of events that are not, in the end, important. Whilst it may be that few tangible things 'happen', in terms of policy or practice, small changes are experienced as huge successes.

In this section I discussed literature from social movement scholarship, outlining key debates around how different forms of politics are understood. I draw from this scholarship to conceptualise activist politics, making clear that I am influenced by the frameworks related to both prefigurative and otherwise politics, though in different ways, as will become clear in the following chapters. By using these two concepts, I am motivated by the desire to not always pursue theoretical determinacy (as in much feminist scholarship; see especially de la Bellacasa (2018). Rather, my work is situated somewhere between these literatures. The reasons for this will become clearer in chapter 6, when I show how activists' keep politics in a state of indeterminacy. By examining how activists build indeterminate worlds, my thesis contributes to anthropological explorations of what constitutes political action and organising. The concept of indeterminacy has not yet (as far as I am aware) been examined in this way as a form of intentional/agentive politics.

VI (v) Healing

I turn now to explore the concept of healing, since this is central to my analysis of mental-health activism. The term 'healing' is commonly used across mental-health services to depict the treatment of and recovery from illness. At times, scholars use healing as a catch-all signifier of all processes associated with wellbeing and health that are *not* biomedical, thereby jettisoning the concept to the realm of 'alternative' medicine (see e.g., Vaughan 1994; Strathern and Stewart 1999; Rivkin-Fish 2016; Sik 2021).[60] Some scholars utilise the term without defining it, as though there were a generic, coherent framework (see e.g., Rivkin-Fish 2016; Csordas 2017). In this section I explore how healing is conceptualised in studies that *do* attempt to define the term.

I argue that healing has been overdetermined in mental-health services by the logic of linear progression from sickness to health, this logic also being reflected in work by some

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[60] The term 'healing' in anthropology has mostly been applied to indigenous and 'non-western' approaches/medicine (c.f. Asuni 1979; Desjarlais 1992; Csordas 2004; Atewell 2007; Sax 2009; Bellamy 2011) rendering the term neo-colonial.

medical anthropologist. I argue that, like political action, healing is an experience that is always in the process of becoming. This framing contrasts strongly with many literatures on healing and treatment in mental health that share an assumption of 'finalisability'; meaning that the healing process has a final endpoint, or cure (Chase 2019). To take just one example, Kirmayer's conceptualisation reflects the ideation of healing as involving "a basic logic of transformation from sickness to wellness that is enacted through culturally salient metaphorical actions" (2013; 39). This definition, which resonates with much health services literature, rests on the notion that healing occurs through a direct trajectory moving from illness to wellness. Kirmayer remains committed to this progressive logic despite recognising that healing varies personally, socially and culturally. The *Encyclopaedia of Medical Anthropology* provides a similar perspective, in that it defines healing as 'a complex process that starts with a patient's experience of something being wrong and proceeds to some form of diagnosis and then possibly treatment' (Ember and Ember 2004; xxxi). Even though this definition focuses more on the experience of treatment than illness, it still advances the notion that healing entails evolution from one state to another.

The difficulty with such narratives is that they present mental distress and its consequences as though they are a problem to be fixed. Consequently, the ideation of recovery puts pressure on those experiencing distress by creating the expectation that they will be 'cured'. These narratives also disregard the highly variable nature of healing, insofar as the process does not necessarily entail an end point.[61] The recovery narrative is explicit in the 'recovery model', which is becoming increasingly prevalent in mental health services in the UK. Originally designed to ensure that those experiencing mental illness have a sense of hope, the intention underpinning the model is also to give citizens greater responsibility for their own health and wellbeing (Edgley et al. 2012).[62] However, critics of the model reject its assumption of coherence (*ibid*; Kaiser et al. 2020). They also argue that conceptualising recovery as linear implies that affected individuals are damaged, broken, or ill, and need to be 'restored' to their prior condition.[63] Several anthropologists have tracked the impact of 'recovery narratives' in mental-health provision

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[61] This argument has also been made in studies on ageing, disability and chronic illness (e.g., Shield 1988; Kaufman 2014; Pols, Pasveer & Willems 2018).

[62] Yet there remains strong debate about whether this form of 'self-management' facilitates patient empowerment or simply reduces the financial burden on the state (MIND 2008).

[63] For an interesting comparison, see Mattingly and Myers' conceptualisation of moral 'repair' (2016; 2018) which embodies similar notions.

(Jenkins & Barrett 2004; Long & Moore 2012; Whitley 2014). They show that these narratives can put inordinate pressure on service-users, in that the notion of recovery perpetuates norms that patients struggle to aspire to. Failure to 'recover' may undermine an individual's sense of self-worth, thereby exacerbating their distress. For example, Jenkins & Carpenter-Song (2005) observe that individuals with schizophrenia experience changes in distress as processual and complex, such that there is no progression from 'illness' to 'wellness'.

This literature also finds that when it comes to perceptions around the 'requirements' for recovery there is often a mismatch between the views of service-users and those of service providers (see esp., Estroff 1981; Desjarlais 1997). [64] Thus, service-users commonly struggle to comply with the norms applied in standardised therapies, treatments and "prescriptive possible pathways" (Blencowe 2018; 15). Others still have connected the British Government's promotion of recovery in mental health with a desire to reduce the mental health 'burden' on the welfare state. This is seen, for example, in the intertwining of 'back to work' programmes and recovery initiatives, where the aim is to enable people who are sick to recover to the point that they can function as productive citizens (Perkins and Slade 2012). I argue that these kinds of conceptualisations— whether employed by mental-health service providers or medical anthropologists—serve to marginalise individuals with mental-health diagnoses, relegating them to the realm of incomplete persons requiring readjustment. In turn, such conceptualisations serve to consolidate and reproduce relations of power that are prevalent in medical settings. I show that activists problematise this approach to alleviating mental distress and work instead to keep healing approaches 'open'. By enacting mutuality, they also reject the dyadic model of healer and healed that dominates conventional therapeutic approaches in the UK.

Having examined some of the assumptions in the literature, I turn now to the question of how mental-health activists conceptualise healing. What counts as healing is an inherently political question that reflects hierarchies of knowledge and power, which in the context of mental-health activism sets actors against 'the state' and service providers. That said, activists' notions of healing are not monolithic but rest as much on diverse and changeable ideological commitments as on everyday praxis, making it hard to arrive at a decisive and

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[64] In regard to psychiatry in particular, critics have argued there is a political and economic dimension to emphasising cure and recovery. For example, historically, schizophrenia was treated as a non-curable disease, with dire consequences for patients, including lifelong institutionalisation. Contemporary approaches recognise people's ability to change and recover.

coherent definition. What all activists recognise is that healing is a fundamental feature of daily life rather than an outcome of clinical procedures. They acknowledge that it involves different things for different actors at different times; sometimes healing is about a momentary feeling of belonging, and at other times it is about small achievements—such as restricting the access of NHS staff or civil servants to a building. In this sense, healing is seldom regarded as finite or an end, so much as a means, or process, one that is about 'becoming'. The healing process is dynamic and fluctuates over time. It is replete with highs and lows and involves many moments when nothing happens. There are even moments of seeming regressions—such as mutual hurt or suffering; yet these too can be points of relatedness and understanding. This suggests that healing, distress and wounding are not diametrically opposed to one another but rather in continuous relationship. Moreover, the process of healing does not 'flow' straightforwardly from healer to patient but breaks down boundaries that normally separate service-user and service provider. For example, Hsu (2005) demonstrates in her ethnography of acupuncture that the acupuncturist feels the patient's pain through her own body, and this creates a sense of connectedness between them.

Thus, activists do not think of healing as the role of specific individuals but rather a collective responsibility.[65] Healing is brought about intersubjectively, through attunement and mutuality as well as engagement in prefigurative and otherwise politics, and also integrates spatial and temporal elements (chapters 4, 5, and 6). Hence, I turn now to literatures that analyse politics for potential, such as critical hermeneutics. I draw on phenomenological studies of healing, such as Koss-Chino's (2006) exploration of transformation among spirit healers as building the capacity for relationality and empathy. I have found Raschig's work particularly helpful in this regard. For Raschig, healing in the context of an *otherwise* politics is "not an anticipation of a healed state" but "a modality of being through which [interlocutors] encounter, understand and inhabit the happenings of their lives differently" (2016; 31). Again, rejecting the idea that healing is a finite end, Raschig understands the process in terms of actors orienting themselves in the world. Healing is a holistic, social project—an assemblage of social processes—a way of encountering and creating life 'otherwise' in contexts where every day experiences of living disenfranchise and isolate certain groups. In other words, Raschig (2016; 73) takes healing to be a way of 'reworking' woundedness from past and current experiences. In a

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[65] Scholars such as Póltorak (2007) and Overring and Passes (2000) have made this argument in relation to several non-western medical systems (in these cases, in Tonga and Amazonia).

similar vein, in interpreting activists' mode of healing I have chosen to maintain analytic openness to variation and nuance. I look beyond the individual healing experience, deemphasising the individual as the centre of meaning. For activists, healing is part of a larger, dynamic system; the fewer the rules and restrictions regarding healing, the better. In this sense, I aim to show how activists' holistic approach can be described as indeterminate.

VI (vi) Revisiting kinship and care

In this section I argue that the concept of mutuality is a useful analytic tool for depicting the complex configurations and dynamics of activist sociality. I explore different facets of mutuality and argue that the concept enmeshes elements of relatedness, care, support, politics and sociality, all of which are, for activists, essential to healing.[66] I discuss the theoretical underpinnings of the concept, as articulated in the anthropological literature on care and kinship. In doing so, I am aware that many activists reject the concept of 'care', and especially its usage in mental healthcare settings.[67] However, I suggest that despite this, some anthropological interpretations of the concept remain pertinent to this thesis. In particular, I refer to a recent body of work in the anthropology of health that is concerned with the 'dark side' of care. I conclude the section by showing why I have chosen to use the terms mutuality and relatedness, arguing that these concepts are particularly relevant to activists' stance.

The problem with care

Here, I explore how care has been theorised in various literatures, highlighting both the useful and problematic ways in which it has been interpreted. Anthropologists have shown that universalised assumptions around care are in practice built on the specific "ways in which care is structured in contemporary Euromerican capitalist states" (Thelen 2021; 18), according to values of 'individualism, rationalism and independence' (c.f. McKearney 2021; non-paginated). Aiming to counteract this 'silo'ing of care and its compartmentalisation in social life, de la Bellacasa (2017)[68] recently suggested that we

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[66] In making this case, I foreground the empirical evidence provided in chapter 5, in which I explore how activists often prioritise support for fellow activists over many other aspects of life, including their own mental health.

[67] Partly because of this, I use the term 'support' throughout instead of care.

[68] Along with other feminist theorists, e.g., Butler (2005; 2009).

should think about the labour, practice, affect and ethics of care in broad(er)terms, as a process involving many layers of complexity. In other words, the concept of care needs to be expanded and considered as existing outside of dualistic relationships, and specific spheres of activity (such as the home or hospital). Like Schlecker and Fischer (2015), de la Bellacasa rejects the tendency towards binary conceptualisations—such as 'care giver' and 'care receiver'—and the opposition of 'affect' and 'efficiency' as found in many interpretations of caring relations (c.f. Tronto 2013; Alber and Drotbohm 2015). Similar binaries are replicated in the literature on social support, wherein relationships involving kin and friends are assumed to arise more 'readily', than relationships built around intentionality and purpose, as with professional carers and charity volunteers (c.f. Ben-Amos 2008; Kay 2011; Rice et al. 2013). Implicit in these dichotomies is the notion that care providers are more powerful socially and more capable, than are recipients of care—who tend to be conceptualised as vulnerable, needy, dependent and deserving (Glenn 2010; 96).[69]

Activists do not conceive of care this way; nor do they accept the dichotomy between powerful and powerless in care relations. I demonstrate in chapter 5 that activists commonly associate conventional relations of 'care' with coercive, non-consensual interventions (such as enforced drugging) that replicate structural inequalities. In activists' minds, this kind of 'care' would have been prohibited were it not for their having been diagnosed as mentally ill. Interlocutors often speak about caring roles in the context of distress as undermining their independence and making it hard for them to engage in positive, equal relationships. Being identified as a 'caregiver' can lead to being ostracised and isolated socially, as I show in chapter 5. In the context of activist networks, caregiving and receiving are difficult to distinguish and closely intertwined. I therefore suggest that the role of 'caregiver' and 'care receiver' are not opposed subjectivities, and that formulations in which they are conceptualised as binary roles negate the dynamic relational processes underpinning the mutuality of support (Miller 1994).

'Self, other' and the project of mutuality

A significant body of anthropological literature conceptualises care as an orientation towards the other (e.g., Conradson 2003, Kleinman 2012). But what if care is without bifurcations

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[69] Care can be socially powerful act. For example, Mittermaier looks at the ways in which care can "enhance personal status and power" among people involved in social justice movements (2006;26).

such as 'self and 'other'? de la Bellacasa (2017) argues that in practice care extends to a range of acts and circumstances, including those less intentional acts that form part of moving through life with others. For her, 'care' is about accepting that we are all intertwined with each other, through our very existence, and that therefore, we inevitably affect each other. This understanding of care resembles critiques of the traditional anthropological notion of exchange (i.e., Widlok 2017), which is often framed in terms of dyadic transactions between two parties (Mauss 1924). Widlok (2017) argues that this understanding does not allow for the nuances of sharing economies, which are built on unequal (or non-reciprocal) transactions. [70] Widlok (2017; 23) writes that in sharing economies,

> …one and more people may be involved in the same parallel sharing events, sometimes as giver, sometimes as receiver [or both]. But these events are not connected to one another in the same way as they are reciprocal gift giving. Instead, the social system depends (more or less) on everyone providing (something) at some stage.

Thus, in sharing economies the obligation to reciprocate is subsumed into wider networks. I highlight this process in chapter 5, pointing out that among activists collective and self-support are not incompatible. Applying the notion of generalised exchange to activists' case highlights how the distinction between 'self' and 'other' can become less important, even destabilised. The way activists 'care' is not entirely outward looking (i.e., collective or social); nor is it comparable to individualised forms of 'self-care'. For activists, mutuality entails multiple individual exchanges that extend in many directions and are part of a wider system of circulation. This is similar to Graeber's understanding of communities in Melanesia as being interwoven with relations of "individualistic communism"; personal one-to-one relations that operate, to varying degrees, "from each according to his ability, to each according to his needs" (Graeber 2001; 104-105). Like Widlok, Graeber contends that "the possibility that "gifts" operate *without* transactional logics (i.e., with money, or expecting something in return) is often overlooked" (2010; non-paginated). Accordingly, for activists, it is not necessarily that the 'gift' of support be reciprocated by the receiver; rather, it is projected outward to the wider group, as part of the broader project of mutuality.

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[70] Widlok argues that attempts to highlight the potential inequalities of exchange (e.g., Bearman's (1997) notion of 'delayed' reciprocity, Sahlin's (1998) 'generalised reciprocity' and Peterson's (2013) 'asymmetrical reciprocity') assume that the process of exchange involves two-way transactions, in which the burden falls on those individuals directly involved.

In other words, acts of support work more like a shared economy, rather than centring around the self / other dyad. Activists do not expect a direct return so much as enact mutuality by moving through life with others.

Is care 'good'?

I am critical of how some anthropologists associate 'care' with positive forms of social cohesion. This legacy stems in part from the ideas of theorists such as Durkheim (1897), who argued that social cohesion is the absence of conflict or crime. In contrast, I contend that mutuality is, in fact, constituted by conflict and inseparable from inequality. 'Care' (and especially caring for *kin*) is often discussed unambiguously as a highly moral practice (Alber and Drotbohm 2015; 9; c.f. Thelen 2015). One body of literature, in particular, focuses on the intentions of carers, arguing that caring is based on expectations that actors 'do good' (i.e., Kleinman 2012; Buch 2013; Black 2018). For example, Kleinman maintains that care is a moral necessity, a cultivation of the person associated with sensibilities such as "empathy, compassion, respect, and love" (2015; 1550). The problem with representing care as a positive, moral, value-driven aspect of social life is that care may 'harm' those involved, and that what *resembles* care, can also be seen as a form of coercion (cf. Garcia 2010; Stevenson 2014; Pinto 2014). As McKearney reminds us, "whether or not an action acquires the moral status of "caring" depends on much more than people's *intentions* or their understandings of the good. It must be established in the vicissitudes of relationships" (McKearney 2020; 224). McKearney also points out that we can never know how care is received—in that it may be experienced as harm.

Recently anthropologists researching care in health contexts have begun to examine professional peer support and other forms of care. Their work demonstrates how these structures can "create and perpetuate the suffering they purport to treat" (Kennedy 2018); this is the 'dark side of care' (Lester 2018; Cubellis 2018). Geschiere (2003), for example, highlights aspects of power inherent in care that can be tricky to navigate.[71] He points to the need for more 'nuanced' notions of care that consider the danger and aggression that might suffuse close social ties. In doing so, his analysis problematises the assumption that sociality is premised on a 'real unity' between people (Gilbert 1997: 23). In practice, power is inherent in all aspects of social life, and social theory needs to engage with the

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[71] For other studies that theorise care as a form of power see (Lindenbaum and Lock 1993; Robinson 1999; Fassin 2007; Feldman and Ticktin 2010).

consequences, as Wacquant warns, "contention… is the ubiquitous feature of collective life… [and] struggle… the master metaphor" (2006; 4). Studies of intentional communities (e.g., Brown 2002; Sargisson 2010) have also shown that "aspirations to harmony and commonality flounder in the face of conflict, discomfort, and emergent hierarchies" (Lockyer 2007; 186), thereby impeding members' aspirations around communality (Long and Moore 2012; 104). Similarly, Aulino (2019) demonstrates that while Thai values of care aspire to religious harmony, they can in practice aid oppression and structural violence. Along similar lines, I demonstrate in chapters 4 and 5 that activists' desire *not* to enforce rules, boundaries or regulations around mutuality, means that the provision of support often places pressure on particular individuals. Chapter 5 explores what happens when actors fall into such roles, particularly when faced with the challenge of supporting peers in an individualising mental healthcare system. Thus, to summarise, pertinent to this thesis are the few studies that show how attempts to care can be *both* harmful and coercive, as well as beneficial to those involved. This literature makes clear that it is not easy to define care as a 'good' or 'bad' force, and that doing so would neglect the lived complexities of care relations.

When care involves kin, alongside moral norms it can cause deep ambivalence and uncertainty, in turn blurring boundaries and understandings of kinship. In her thesis on the experiences of people in the UK who care for kin with dementia, Kennedy (2018) explains that care can be experienced by both parties as a 'threat' to, as much as a reinforcement and signifier of, kinship. She cites examples, for example, when someone is looked after by an intimate partner this threatens to disrupt the conjugal bond and locate the relationship within the realms of carer/cared-for. Similarly, when relatives keep a close, watchful eye on individuals with dementia this may make those individuals feel as though they are under surveillance and infantilised. Pinto's (2014) ethnography with women in northern India also highlights the ambiguity of caring relationships. She writes, "the vitally important work of finding a way through a life with others, and of illness and healing, happens at points at which freedom and abandonment, or care and confinement[are]not easily distinguished" (Pinto 2014; 252). These studies position care as both a potential threat to and a maker of kinship; if enacted in the 'wrong' context, or by the 'wrong' person caring can be a force of coercive power and wounding. Such accounts lend insight into aspects of care that have been neglected in earlier literatures.

I have shown that the term 'care' has historically been bound up with unhelpful dichotomies, which, as activists themselves point out, position caring relationships in dyads. Activists reject 'care' as an unequal practice stemming from capitalist health and welfare systems. It is not my intention to evaluate what for activists counts as 'care', so much as to reveal the tensions and difficulties they experience as they struggle to enact mutuality in the face of precarity, strive and exposure to individualising health systems. In the next section I argue that, similar to models of sharing economies, mutuality offers a more diffuse model of caring relations. By demonstrating that mutuality can be ambiguous, I hope to trouble the dichotomies in the literature between good and bad care (c.f. McKearney 2020) and also to reveal some of the darker sides of support and how these can in fact reinforce mutuality. The ethnographic accounts I provide in chapter 5 demonstrate that conflict and interpersonal distress are tangible and unavoidable parts of living lives together. I show how patience and permissiveness in relation to conflict and discomfort can reinforce a sense of relatedness, security and belonging. In this sense, mutuality is not a given, but shaped by specific situations and relationships.

Thus, I argue for a nuanced, intersubjective understanding of the concept of mutuality, accounting not just for interdependence and sharing between actors, but also for conflicts arising out of living lives alongside others. Chapters 4 and 5 explore how mutuality is conceived of collectively and is only interventive when consensual; a key feature of mutuality being that it allows for individual autonomy and freedom.[72] Thus, my argument is that mutuality encompasses collective belonging as well as individual difference.

Relatedness

I begin by exploring relatedness as an important feature of mutuality. Historically, many anthropologists, particularly in the 1970s, made the assumption that kinship was the starting point for care (Thelen 2021). Like care, kinship was commonly characterised in terms of 'unconditional amity' (Sahlins 2011: 235). However, Carsten (2000) proposed the term 'relatedness' as an alternative to kinship, on the grounds that the latter construct had traditionally been overly romanticised. For her, the notion of 'mutuality of being', coined by Sahlins, presents an unrealistically optimistic view of what it means to be intersubjectively

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[72] Although not a focus of my research, consent was an important debate among activists. I observed that intervention only happened when people could give consent through clear, active signals. But I did hear of a few cases where people had supported individuals who were not able to give their consent. Usually, if they feared they might become too distressed to decide for themselves, activists would try and plan for this eventuality in advance by informing others of their wishes.

connected, in that it invokes "a warm, fuzzy glow rather than a cold shiver" (Carsten 2013: 246). According to Carsten, relatedness emphasises how we are connected with people socially, materially and affectively, in ways that also encompass contestation and conflict. She describes relatedness as an "area of life in which people invest their emotions, their creative energy, and their new imaginings" (Carsten, 2003:9), so that an individual's pain can be dispersed and shared with others, this creating social bonds and a sense of belonging. Schlecker and Fleischer (2012) suggest that the feeling and experience of 'relatedness' is also central to healing encounters.

Relatedness has important implications for how we live our lives with others. It suggests that connection and intimacy can be constructed through lived experience rather than merely as a consequence of the more formal ties of blood and marriage (Carsten 2000; 1). It is a rejection of the focus on blood relations in kinship studies and a recognition of different constellations of 'families' and social networks. As opposed to the 'inherent' ties implied by consanguinity (as in classic understandings of kinship), relatedness draws attention to the intersubjectivity of actors, by emphasising the ways in which people are inter-dependent and the importance they grant each other in their daily lives. [73] Accordingly, I understand activists as enacting relatedness, rather than kinship. In chapter 5 I discuss the affective bonds forged by activists who share similar conditions of precarity. I also examine how interlocutors feel more akin to one another and come to depend more on each other than they do on family members.

Much like the literature on care, Schlecker and Fleischer (2015; 1) argue that anthropological literature on social support has (unwittingly) approached the subject in terms of "efforts to alleviate and overcome the state of affairs" rather than examining situations in which support has unfolded in less straightforward ways. They write about mutuality, which they see as concerning what happens *between people*, rather than the explicit functionality or strategic conduct of support. As such, mutuality is "beyond dichotomies of self, other, individual and society" (ibid; 2).[74] However, in the ethnographic

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[73] Relatedness is proposed as a counter to classic understandings of kinship (sometimes referred to as 'pre- Schneider' (1984) understandings of kinship) such as in the studies of (Evans-Pritchard 1951; Firth 1956; Gellner 1960; Beattie 1964).

[74] Schlecker and Fleischer acknowledge that mutuality owes much to Mauss's concept of gift as productive of sociality, as well as Overing and Passes' (2000) exploration of conviviality in Amazonian sociality, which also circumvents distinctions between self/other and individual/society.

contexts explored by Schlecker and Fleischer [75] mutuality is *not* a kind of automatic solidarity, as Durkheim (1897) might have framed it. The term 'mutuality' draws on Sahlins' notion of 'mutuality of being', which highlights how affective and material experiences, such as the sharing of food, memories and suffering, shape relationships and create affinity (Sahlins 2011: 5-11). Sahlins argues that "experience is more than the individual" (Sahlins 2011: 3) and points to how people "live each other's lives and die each other's deaths" (Sahlins 2011; 2). [76] Mutuality emphasises how relationships are mutually constitutive and entail "existential sharing…a desire to be virtuous or a longing for conviviality" (2013; 12). [77] In building on these ideas, Schlecker and Fleischer's conceptualisation also recognises the more 'negative' aspects of care, a dimension of relational practices that Sahlins tended to neglect. Drawing on these ideas, I examine how interlocutors forge mutuality in contexts of distress, highlighting how it involves "the slow intertwining of lives with others" (Al-Mohammad and Peluso 2012; 52). I conceive of mutuality as the "mutual search for compatibility among differences", also contending that it is not always cooperative (EASA 2008). That said, it is important to note that 'mutuality' does not mean that feelings or practices between persons *are* 'mutual', rather it highlights the *intention or desire* that they should be (as I show in chapter 6).[78]

In investigating the complexities and contradictions embodied in activist practices of mutuality I suggest that relationships are negotiated and co-produced as much by contestation and struggle as through unity. In activists' relational practices mutuality exists without clear norms as to how persons might support one another, such that "lines of care and concern emerge, are fostered and also frayed" (Al-Mohammad and Peluso 2012; 42). The 'taken for grantedness' (Lazar 2012) of mutuality means that it is found in the dynamic between spontaneously responding to another's immediate needs in the moment and feeling obliged to care. In other words, mutuality can be costly emotionally because it may mean individuals give too much of themselves.

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[75] Their case studies were undertaken primarily in urban environments in Hong Kong, Korea, South Africa, Portugal, Russia, China, Greece, Vietnam and India.

[76] In chapter 5, I show how the imaginative work of mutuality has affective and physical consequences; for example, members of FLL and SAP became intensely distressed when Andy went missing as they believed he might be suffering. Remembering what it is like to be in his place, activists expressed feelings of loss and existential anxiety.

[77] Póltorak also notes that for Tongans the discourse of 'ofa' (love, mutuality) is not a representational but a social strategy: it makes mutuality more possible, and easier to return to after it has been broken (2021, pers. Comm.)

[78] Social movement scholars have debated the concept of 'solidarity' in a similar way, arguing that solidarity is an expression, intention and affiliation rather than an account of how relationships actually are. Similarly, I contend, mutuality is not an all-encompassing way of describing sociality.

Both mutuality and healing are intertwined in activists' worldbuilding as a project which is both present-looking and future-oriented. By examining activists' experiences of mutuality, I find that healing does not necessarily take place at a specific time, location, or involve specific individuals, but rather, is a dynamic, process (Benhabib 1985) that is both timeless and entails 'caring with' persons (Tronto 2013;11). Activists reject exclusivity, egoism, competitiveness and efficiency and spend considerable amounts of time carefully attending to each other. Yet, the ethos underpinning their relational practices also allows space for self-expression and individual autonomy. Thus, it makes sense to look at mutuality in terms of the intersubjective experiences, the intangible, diffuse, in-between things, moments (Al Mohammad and Peluso 2012) and 'encounters' (Fleischer and Schlecker 2015), that produce activist sociality. Attentiveness to the everyday interactions and experiences shaping interlocutors' wellbeing, assists in defining a more nuanced, subjective understanding of the notion of mutuality (and in turn, care) and is one of the key theoretical contributions of my research.

VI (vii) Chapter conclusion

I began this introductory chapter by outlining the broad distinctions between psychiatric conceptualisations of mental illness and activist understandings, pointing out that 'mental distress' is the preferred term in activist circles. I explored the notions of structural violence and social defeat and argued that they are incremental to anthropological explanations of how mental distress is shaped by social contexts. In the case of mental-health activists, financial precarity, insecurity, chronic stress, and social stigma, together with adverse treatment experiences, are key drivers of mental distress. I introduced the concept of the 'shadow of biomedicine' to convey the very real sense of the 'absent presence' (Gilsenan 1996) of biomedicine in activists' lives. Thus, my data both confirm and complicate anthropological conceptions, inasmuch as actors negotiate clinical encounters (chapter 3) and reframe structural barriers, defeats and disappointments as part of their politics, defining them as successes (chapter 6). I also suggest that in emphasising the power of structural forces, it is important not to negate individual factors. It follows that mental distress cannot simply be seen solely as an outcome of structural violence or social defeat.

In the second section I outlined the analytical framework I use in examining politics and social movements. I argued for a marrying of social movement scholarship with medical

anthropology and critical phenomenology in order to enhance studies of therapeutic sociality. I suggested that the theoretical constructs of prefigurative and otherwise politics are appropriate for explaining the diffuse and informal character of activists' political processes as well as for revealing how activists' personal choices and daily ways of living foreshadow the kinds of futures they aspire to. I went on to highlight how prefigurative and otherwise politics are central to activists' understandings and experiences of healing, in that both processes are conceptualised and purposefully kept indeterminate. I argued that indeterminacy should be emphasised as a novel way of understanding political action and organisation among activists. I re-examined normative notions of healing, which assume a linear treatment trajectory from sick-to-cured. Nor is healing confined to the realm of binary oppositions such as 'self'/ 'other' or 'individual' / 'collective'. In this way, I have expanded the notion of healing as it has classically been framed in mental-health provision, where it is reduced to particular logics associated with dyadic healer/patient relationships. Beyond this, I argued that activists' informal and diffuse modes of sociality are constructed in opposition to institutional constraints, and bureaucratic management and accountability systems. For activists, healing is an intersubjective experience that is always in the process of becoming and is thus indeterminate. Reformulating distress, healing, politics and care as processes defined by indeterminacy adds fresh insights into activists' experiences of healing from mental distress in the UK and is an important shift away from perspectives that are oriented around individuals, services or clinics, to one that is more situated, processual and spatialised.

Finally, I advanced theorisation within the anthropology of care by adding to Schlecker and Fleischer's concept of 'mutuality' with a more nuanced, intersubjective understanding in the hope that this will enable a better understanding of emergent forms of sociality among activists. I highlighted how living lives alongside others can give rise to conflict. In other words, activist mutuality and politics are not free from power asymmetries, contestation and the like. In fact, throughout this thesis I show how mental health activists both accept and work with the 'positive' and 'negative' aspects of sociality.

Chapter 1: Methodology and Ethics

1.1 Chapter introduction

In this chapter I explore the methodological choices I made during fieldwork. I examine how particular characteristics of the field influenced my theoretical framing and interpretation of the data, especially my adoption of a critical phenomenological and hermeneutical approach. Fieldwork experiences were heavily shaped by concerns around identity and trust; thus, my positionality is an essential part of methodology. I trace key transitions, including how interlocutors changed from being cautious and maintaining a wary tolerance of my presence to establishing strong ties with me, which have lasted into the present day.

I begin by introducing some basic characteristics of interlocutors and the specific contexts of mental health activism in London. I discuss the fieldwork settings and describe some of the adjustments I made in order to ensure that the research would be effective despite some of the constraints associated with both the topic and the complex lives led by interlocutors. I outline the research methods in detail, discussing the reasons why participant observation was by far the most appropriate method in this context. I follow with a discussion of how my identity, positionality and activists' relational ethics were vital to building relationships and participant observation. I touch upon the specific dynamics of urban ethnography and the character of the 'assemblic' field (Zigon 2015). Finally, I discuss ethics, followed by a reflexive analysis of ethical considerations, a topic which is incredibly pertinent to my research.

Finding the field

This study is based on fieldwork undertaken in London. As the primary site of the UK's Occupy movement and the main centre nationally for mental health activism, the capital is in many ways a particularly appropriate location for doctoral research on this topic. [79]

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[79] Although there are some activist groups in northern England, associated with universities, activists have noted that mental-health activism in the UK is very London focussed. London is one of the main places where activists gather, most likely because of its sheer population size as well as the presence of mental-health hospitals and other institutions, such as The Tavistock Institute and Bedlam Psychiatric Hospital (see chapter 4), that have historical and political significance in this field. At the same time, the

However, London is a difficult and complex location for fieldwork, and it presented me with a number of challenges. The fieldwork took thirteen months, between August 2018 and September 2019 and, as I note in the prologue, built on ethnographic research undertaken for my MSc (Pratt-Boyden 2012; Howard and Pratt-Boyden 2013). My engagement with mental-health activist groups during MSc fieldwork greatly facilitated my entry into the field. The initial goal of the MSc research was to explore the aims, organisation and strategies of the Occupy London protest camp, my interest in this enquiry being the engagement of social movements in the development of social relations which prefigure a more 'democratic' and 'empowering' world (Guerlain and Campbell 2016). However, as I note in the prologue, during fieldwork I became fascinated by the infrastructure of mental health support offered to camp inhabitants and others who were experiencing various forms of distress. This support involved an explicit rejection of conventional treatments, and their replacement with a range of novel approaches and practices. Realising that this topic merited far greater attention, it eventually became the focus of my doctorate.

Also as mentioned in the prologue, following the eviction of the Occupy camp, a small group of former members decided to set up an intentional community and moved together into shared accommodation. My original plan was to explore this initiative by living and undertaking participant observation in the squat. However, a couple of months before my fieldwork began, the community was evicted, and its members moved into mostly very precarious accommodation spread across the UK. So, I was forced to abandon this idea. Fortunately, some of its members remained in London and became my key interlocutors. In time, they introduced me to other activists, in the manner of a snowball sampling technique. This allowed me to build up a fairly large network of activists with whom I could conduct my research.

Having been advised by one of my contacts that the East End is a hub for mental health activism, I moved into rented accommodation in the area. My room was just a few minutes away from the venue where a local anti-capitalist mental-health group held their weekly meetings—these being focussed on connecting distress with wider political processes and events. *Health As Disobedience* and similar groups were also operating in the area. Prior to undertaking fieldwork I was not aware that, as one of the most deprived boroughs in

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City of London's financial and banking district is an important symbol of capitalism, where activists can protest with high visibility. London was also a key point of convergence for the Occupy movement in which many of these actors were involved.

London (as measured through household income, housing, services, crime, health, living environment, employment and education), there are also a large number of mental-health services in the area.[80] On arrival, I tried to narrow my field location down to a smaller and more manageable community by mapping out the key sites of activism locally. This meant exploring the history of (long disbanded) a wide range of groups, including the Hackney Mental Patients Union (MPU), Hackney MIND advocacy service (known locally for being more radical than other MINDs), Hackney Patients Council, The Friends of St Clements, Campaign Against Psychiatric Oppression (CAPPO), as well as tracing activists' use of local premises such as Kingsley Hall.[81]

However, it soon became apparent that in spite of the long-term concentration of mental-health activism in the East End, I would not be able to do full justice to the topic by confining myself to a fixed field site. Focusing on local activist venues left me with a sense of 'incompleteness'. Activists frequently travel far beyond London's East End to visit other activist groups and individuals, as well as for DWP and medical appointments. Indeed, rather than the East End, central London is often the preferred location for activist events—for example, protests, seminars and conferences—since it provides them with greater visibility and impact. Even when not directly engaged in activism, many of my interlocutors spend their days moving around both within and outside London, whether to socialise, shop, exercise, work, or volunteer, or to attend the multitude of free activities hosted by mental health organisations and grassroots groups.[82] Many also live in social housing that is spread throughout the city.

The dispersion and mobility of my sample, and activists' use of space more generally, was challenging. Individual field sites (for example, Kingsley Hall and the social hub frequented by Friends of London's Loons (FLL) were at least 5 miles apart and also quite distant from my lodgings. The two locations that I frequented most often were a full thirty-two miles apart. The logistical challenge was compounded by the fact that I regularly needed to visit several different locations in a week, and on particularly busy days might need to visit as

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[80] Bryan assured me that East London in particular was 'the place to be', due to the strong historical connections between the East End and mental health activism. The area's importance as a centre of activism is reflected in its extensive documentation by the Survivor History Group (n.d.).

[81] The home of R.D. Laing's well-known experimental therapeutic community. I discuss this building further in chapter 4.

[82] One interlocutor carefully maps his week according to the different (free) activities offered by different services across London. He spends his days travelling widely (using free bus passes or walking) across the capital, eating breakfast in East London, attending a philosophy class in West London, dinner in South, and attend a singing class in North for example.

many as three.[83] The situation was more manageable when there was less going on and sometimes I was able to attend the same field location on several consecutive days.[84] Initially, I tried to schedule daily visits to important locations, such as activist meeting spaces. But I soon began to receive spontaneous invitations from interlocutors to meet up with them, so my routine changed over time. Chance encounters began to play a larger role in fieldwork, as did allowing time to 'pause', wait for invitations (instead of seeking the field) or rest.

The 'assemblic' field

Although I initially expected to undertake fieldwork with a specific population, or group, located in a specific site, this did not fit the rhythm of my interlocutors' daily lives. Like other anthropologists who have conducted urban ethnography (e.g., Fox 1977; Passaro 1977; Donner 2006), my field site was not a 'given' space and my fieldwork tracked interlocutors' movements across multiple settings. In characterising this kind of approach, Marcus (1998) talks about 'multi-sited ethnography'. However, my fieldwork was somewhat different, since most of my interlocutors live in the UK so it did not mean following them to their countries of origin; nor were their lives associated with particular locations. Thus, Zigon's concept of the 'assemblic' field (2015; 2018; 2019) provides a more accurate characterisation of my fieldwork, in that it involved tracking a "complex phenomenon through its continual process of assembling across different global scales and its temporally differential localization" (Zigon 2018; 23). I found activism to be about much more than participation in specific activities and presence in specific locations. Rather, it is an all-encompassing, peripatetic existence, in which participants live, work and perform activism across practically all aspects of their lives as well as diverse locations. In fact, lack of place-based activity can be seen as a fundamental principle of both the politics and healing practices of mental health activism (see chapter 4).

In keeping with this condition, my fieldwork moved along relations, rather than locations, and was not even shaped by particular topics. Zigon describes assemblic ethnography as addressing "widely diffused complexity that is differently distributed" across local manifestations (2018; 22). He explores "how persons and objects that are geographically,

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[83] For example, I might attend an activist meeting in one part of London, followed by a conference in another location and then by a debrief in yet another site.

[84] The groups, locations and areas are described in chapter 2. Distances are given simply to give a flavour of the extent of the area covered.

socioeconomically, and culturally distributed get caught up in the shared conditions emerging from [a] situation" (2015; 502). This is partly why I did not stick to just one activist network, or one site, but followed complex webs of interconnectedness that are spread across the city. Activists operate more in terms of diffuse networks than coherent groups. In the early days of fieldwork, I attended as many mental-health activist events and conferences as I could. This helped me establish contacts for further research. I also followed the most 'engaged' individuals, these being people who participate regularly in activist events and/or engage regularly on social media. However, I soon discovered that activists' engagement in events and relationships is highly inconsistent. This is evident from the case of Andy. Before I entered the field, he had been a member of Stand Against Psychiatry (SAP) for decades and was a regular attendee at their meetings, but he left the network soon after I arrived, only to reconnect with everyone, before disappearing altogether for the final 6 months of my fieldwork. When interlocutors disappeared in this way, I felt that I had to go back to square one. To mitigate this challenge and gain greater consistency across sites, I began limiting my attendance at meetings to those convened by three core groups (described in chapter 2). Confining myself to researching these groups became one of the few constants to my fieldwork. It provided some welcome routine amidst the unpredictable and disorderly field process, during which many meetings and follow-up discussions were cancelled, interlocutors were absent for long periods without notice or explanation and schedules were regularly disrupted.

Initially, I was mainly confined to engaging with interlocutors in public spaces, often the more accessible locations, such as pubs, cafes, parks, streets, social centres and libraries. This was partly because activists seldom discuss their home lives, or homes and almost never offered to meet me there.[85] Home seemed to be an intensely private space. Indeed, I got the sense that for some home may be a source of embarrassment; several interlocutors remarked nervously that their homes were in a mess. There was also frequent mention of other peoples' homes in disparaging terms, such as 'have you seen his house? Its filthy… he doesn't even sleep in a bed, he sleeps in a chair', or 'she doesn't keep her house clean'. Very few activists own or rent their own accommodation—most are on housing benefit and have an extremely precarious relationship with their

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[85] Although I considered seeking permission to call on people at home, I got the impression that this would not have been welcomed. When I invited people to my home, I was met with much surprise and thanked enthusiastically. Thus, I only went to people's homes when explicitly invited to do so.

accommodation. The few houses I did manage to visit were owned by people who were, in activist terms, relatively affluent—and were talked about as such.

One of the advantages of aligning my fieldwork with my interlocutors' itinerant existence is that this greatly enriched my understanding of their lives, including their experiences of London. In the process, I found myself going to areas whose populations are extremely diverse socioeconomically and culturally; although it took time to learn about the varied demographics of these different sites. I travelled to and hung out in various parts of South, West and East London, few of my interlocutors having much reason to go to the wealthier boroughs of North London. That said, the North is a hub for 'progressive' therapy-training centres and therapists who work from home, so I travelled there occasionally to attend therapists' workshops or film screenings.

Moving between activist groups, events and locations allowed to me to better grasp the entanglement of their existence—both its connectedness and disconnectedness. I came to understand that their world is at one and the same time both highly dispersed and deeply connected. Even within a single week I would encounter the same individuals at multiple events and in multiple locations. Following interlocutors around alerted me to the time (and occasionally expense, although many take public transport which is free for individuals with disability passes) activists devote to travel. Most of my journeys were by bicycle, and very occasionally bus. This gave me an understanding of how congested, polluted and noisy the city is, as well as how difficult it is to navigate, and how keen people are to follow their own trajectories. Yet it also alerted me to the existence of concealed spaces where people can linger out of public view.

Despite the many advantages, assemblic ethnography poses certain problems. Initially, I encountered a dilemma similar to that experienced by Bierski, who, also studying mental-health activist groups in North London, commented on feeling, "a sense of incoherence that came as a consequence of the multi-sited character of the field where […] different settings necessitated divergent focusses" (2014; 19). Conducting fieldwork in such diverse settings was sometimes a bit dislocating and I soon felt the need to instil greater logistical and intellectual coherence. So, in addition to restricting myself to three activist networks, I started following particular individuals in order to understand the specifics of their lives and how different groups and individuals are connected (or not). At first, shifting between locations and groups aroused suspicion in some interlocutors, although later it became a

valued attribute as I was able to be of use to interlocutors in terms of networking and disseminating information across networks (discussed further in chapter 5). Moreover, as indicated, conducting assemblic ethnography in a city like London is extremely time consuming and on occasion, quite costly. For example, the rare visits I made to homes took me on long trips, via multiple train journeys. With individuals, their events and networks scattered across London, this exacerbated the logistical challenges.

Who are Mental-Health Activists?

As one might expect in a capital shaped by superdiversity (Vertovec 2005), activists come from widely varying sociocultural backgrounds, heritages and classes.[86] That said, the majority of interlocutors in the three groups I focussed on are white Caucasians from working class backgrounds, and range in age from the mid-teens to the late 70s, though most are around 30 to 50.[87] Some interlocutors are married, some with children, others are single and others still, separated. Some have known one another for years, whereas others are new to the activist field. Activists have very diverse views on activism and while some use psychotropic medications, others prefer therapies based on essential oils and diet. Some are professionals—for example, teachers, scientists, nurses, office managers, carers, occupational therapists, artists, software designers and cleaners—though the activists I became closest to are all unemployed. It is possible that this particular population was more available to engage with my research because they have more time to spare than do those in employment.

Activists' experiences of mental distress, mental-health provision and activism are incredibly diverse (covered in chapter 2). For example, whereas some have no diagnosis, others have been diagnosed with schizophrenia and others still, with generalised anxiety disorder etc. Psychotic disorders such as schizophrenia are normally considered within biomedicine to be very different from neurotic conditions like anxiety and are therefore treated very differently. But I am more concerned with uncovering the commonalities that unite activists, such as their living conditions and shared desire to live 'otherwise', without overshadowing their personal and social particularities. As Zigon (2018; 17) puts it:

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[86] The concept of superdiversity has been used to describe the particular features of London's complex demographic, especially the unique way that the city encompasses individuals of "new, small and scattered multiple-origin, transnationally connected, socio-economically differentiated and legally stratified immigrants" in a kind of complexity that "surpasses anything that the country has previously experienced" (Vertovec, 2005;2).

[87] It is widely acknowledged within the mental health activist movement that the presence of people of colour has been low, due to different priorities.

…today our concepts must do justice to the complexity of the intertwined global, ecological, and human relationality that characterizes the contemporary condition … the 'us' that attunes is a non-categorizable plurality of singular beings that are neither individuals nor merely part of a collective, but unique instances of being-relational.

Although activists self-identify in diverse ways, they share a common identity grounded in their mental distress, adverse experiences of mental-health provision, and orientation towards alternative modes of healing.[88] As a result, they face similar struggles and have similar hopes and expectations. Above all, they come together to share experiences of feeling stigmatised by mental health diagnoses, disempowered and distressed by formal treatments, and by the precarity and indignity of financial insecurity, poor job prospects, and dependence on welfare benefits. For different reasons, many activists live in a perpetual state of struggle brought about by the conditions they live in.

Researching mental-health activism: specific challenges

Activists are frequently well-informed about the legal framework, policies and services in mental-healthcare and aware of their rights as patients. Many are concerned that the reforms introduced by successive governments have contravened the core values of the NHS, while others decry the dominance of psychiatry and voice grievances about specific measures and interventions.[89] Nonetheless, I found it challenging to obtain information about activists' direct experiences of mental healthcare, especially their diagnoses and the type of treatment they have undergone. Few activists choose to talk openly about these issues. I learnt that this is partly because they consider that by citing clinical diagnostic terms and biomedical treatments, they are awarding these diagnoses and treatments a legitimacy that they perceive to be both inappropriate and unwarranted. Instead, they tend to refer to their experiences of mental-health provision in subjective and often quite emotional terms – i.e., how 'the system' made them feel (which is of

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[88] At times, I refer to activist 'groups' to indicate interlocutors' affiliation with specific bodies, such as 'SAP' or 'FLL', although many belong to more than one group. At other times I use the terms 'community' or 'network' when referring to the wider body of activists and to highlight the connections *between* groups.

[89] The English NHS is overseen by the Department of Health and Social Care, which is spearheaded by the Health Secretary. General taxation provides the main source of funding and is supplemented by National Insurance Contributions and minimal patient charges.

considerable importance to activists) rather than what exactly happened.[90] Moreover, service providers are seldom identified through their role, profession, or name, but rather through idioms that indicate their power, or even their clothing.[91] Thus, for example, clinicians tend to be referred to through generic terms, such as 'psychs'. For instance, when describing how he was discharged from one acute hospital ward, having been sectioned and tried continuously to 'get out', one activist exclaimed, 'I escaped from the psychs'.

The man's account of escaping from the 'psychs' emphasises how trapped mental-health patients can feel. This raises another issue for me. Given the enormous impact treatment has on people's lives, I had expected the specifics of different diagnoses and treatment pathways to matter to activists. For example, arguably, the difference between involuntary and voluntary treatment is important, yet activists rarely distinguish precise diagnoses or treatment pathways, more often describing mental-health provision as though it were a single, homogenous system. Indeed, particular treatments only seem to matter when they are the subject of controversy and protest. The conflation of mental-health services and treatments seems to be more than a mere oversight, or a misrepresentation of an extremely complex system.[92] I suggest that it is due, in part at least, to the pervasiveness of wider accountability procedures and processes across mental healthcare, such that dissimilar treatments are shaped by uniform therapeutic, managerial and economic practices and logics. In other words, activists imagine and experience all NHS mental-health treatments as though a uniform intervention—this being 'Treatment as Usual' (TAU), or the 'status quo' in mental healthcare.[93] More than this, the expression TAU

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[90] Throughout my engagement with mental health activism in London (from 2011 onwards) it has been my impression that the most prominent experience of mental-health services and treatments is a diagnosis of a psychotic illness and treatment using a biomedical pharmacological approach. Far fewer of my interlocutors had been diagnosed with neurotic disorders or experienced psychotherapeutic treatments. It was also a challenge methodologically to ascertain individuals' health diagnoses and trajectories.

[91] Psychiatrists are sometimes referred to simply as 'the white coats'. White coats have been a symbol of the clinician throughout time—dating back to antiquity (Póltorak, 2022, pers comm). During one service-user art workshop, participants were asked to draw a psychiatrist, and most drew white, clever-looking men, with clipboards and white coats. When asked what the white coats symbolised, participants explained that they made health professionals seem 'generic', 'cold' and 'authoritative'. One interlocutor explained that she based her decisions on whether to trust a psychiatrist on what they wear; for example, if they are clean, whether their clothes are expensive, if they wear jewellery etc. She felt that the more expensively dressed they were, the more questionable their intentions (e.g., to make a profit, not 'caring' about people).

[92] A specific example is the lack of distinction between psychiatry and psychotherapy, subdisciplines of biomedicine which are conventionally understood to be very different.

[93] As I demonstrate in chapter 3, activists generally fuse the DWP and NHS, regarding them equally as a failure of the state to care for health and benefits recipients.

(sometimes nicknamed 'business as usual') is generally used in a derogatory manner to refer to treatments that are routine, outdated and not attuned to the needs of individual patients. TAU is thought to require minimal commitment from mental-health professionals, and to prioritise time efficiency and cost-savings over patient care. In this sense, TAU does not represent a method or treatment, so much as an attitude and approach to healthcare in general (Blais et al. 2013).[94]

1.2 Research methods

Participant observation

Participant observation was my primary research method. Following Geertz's (1979) 'thick description' approach enabled me to capture conceptions of mental health and everyday supportive practices among activists, along with essential contextual information and implicit evidence. Rapport (2002) points out that when anthropologists undertake participant observation in their own country, language and culture, assumptions are often made about their ability to distance themselves from their interlocutors. However, even though I was conducting research in my country of origin, I was participating in a very different 'world' to the one I usually inhabit. Fieldwork mostly entailed 'deep hanging out' (Geertz 1998) with mental-health activists and participating in their lives and activism. This meant engaging in a range of collective events, including public seminars on mental health, online discussions, conferences, film screenings, peer support group meetings and workshops, *Thai qi* and yoga classes and poetry workshops. It also involved attendance at events that were more explicitly political in nature, such as demonstrations. In addition to collective activities, I participated as much as possible in interlocutors' personal lives, for example, accompanying them to medical appointments and benefits assessments. I also engaged in more informal activities, such as cooking and eating with interlocutors, spending hours with them in cafes, attending birthday celebrations, funerals and very occasionally, visiting their homes. I sometimes travelled outside London (for example Brighton) to stay with interlocutors and take part in conferences and other events.

One of the main advantages of undertaking participant observation with mental-health activists is that the transient, open and welcoming stance of activism facilitates the

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[94] See chapter 2 for a professional definition of TAU as used within medical practice.

inclusion of strangers and newcomers at meetings and other events. This eased my entry into the field and enabled me to forge strong ties with interlocutors, some of whom became close friends, as did their friends, family and allies. Another advantage of working with this population is that activists are continuously engaged in exploring relationality, dialogue and intersubjectivity—even drawing on anthropological theory in the process (such as Littlewood 1987 and Goffman 1961; 1963). [95] Moreover, talking freely with others is encouraged among mental-health activists, who come together regularly to speak about their experiences. In fact, openness and disclosive freedom (Zigon 2015) in communications with others might even be described as the primary ethos that defines them as activists. [96] As a consequence, I did not encounter the kind of challenges experienced by the many anthropologists whose interlocutors are slow or reluctant to share their experiences and views.

Nevertheless, there were times when I felt my 'outsider-ness' (Rabinow 1997) keenly. Researching mental-health activists involved departing from my previous life and playing a part in activist 'worldbuilding'—in other words, assimilating customs and beliefs and participating in activities, some of which were novel and quite strange for me. Sometimes I felt quite awkward, for example when attending funerals, since I was used to these being fairly quiet, intimate events; activist funerals are oriented to large networks and open to anyone. Initially, I focused on researching activists who were well known across networks, whether because they were particularly charismatic, had been activists for a long time, or were involved in its genesis. Talking to these individuals seemed to be something of a rite of passage, and during my early forays into the field I was often told, 'Oh, you can't really understand mental health activism unless you speak to X'. They are invariably the ones invited to speak at conferences and sit on advisory boards and also feature regularly in activist literature and social media postings.

I soon realised that these individuals functioned as a gateway to other interlocutors, since speaking to them demonstrated my sincerity and commitment to learning about the

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[95] Activists tend to engage with texts which critique and expand on western biomedical notions of distress and approaches to treatment. They draw from a rich tapestry of literature including some classic anti / critical psychiatry texts such as Laing's *The Divided Self* (1990) Szasz's *The Myth of Mental Illness* (1961), and the works of Foucault (1965; 1977; 1995).

[96] For example, one of the groups I worked with describe themselves as "not having borders, but mainly centred around South and East London" (2011). The conceptualisation of 'disclosive freedom' is discussed at length in the introduction.

movement.[97] However, while I learnt a lot from such exchanges, I was keen to hear the 'stories' that people do not necessarily think to tell. In fact, the more I listened to the quieter stories, the more I realised that many mental-health activists intentionally resist narrative coherence—indeed, some activists barely spoke, allowing others to dominate conversations. These more private individuals stand in contrast to activists with a more public profile who seek to convey well-articulated accounts of their lives. I attempted to engage with why activists tell particular truths, what their concealments reveal, and what quieter interlocutors have to say.

Many activists live in a continuous state of crisis, whether potential or actual, and suffering is both normal and normalised in this population (see also Al-Mohammad and Peluso 2012). Consequently, I would often find myself listening to deeply personal accounts of an individual's past life and actions, and several of my interlocutors related extremely difficult and traumatic experiences to me. In some of these accounts, they were victims of violence or injustice and in others, they were the perpetrators; either way it was hard to come up with an appropriate response. For example, one man disclosed that he had been raped whilst in hospital, and another told me that, while high on drugs, he had committed rape.[98] A third man described how his leg was broken when a mental-health nurse tried to restrain him forcibly, and a woman related a similar incident, which led to her experiencing an unintentional miscarriage (she referred to as an abortion). Yet another example was when a man explained that his employer took him to court, alleging that he had taken too much sick leave after trying to commit suicide. Engagement in these exchanges required intense, embodied attunement (Ash 2015), such as the adoption of suitable listening techniques, awareness of my body language, and remaining respectful as the narratives unfolded. Rather than interacting with interlocutors verbally, I would listen carefully, often for prolonged periods, nodding my head or gesturing for the speaker to continue talking, as and when appropriate. These methods of attunement conceive of the body as a 'tool for knowing' (c.f. Csordas 1990; Lorimer 2010; Lutz 2017). This is especially true of the affective and embodied aspects of experience, which activists often perceive as vital components of social and political life (Goodwin et al. 2001; Juris 2008; Crossley et al.

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[97] I began to ask questions about what made these individuals so 'special' in the eyes of activists. It emerged that some were known to be particularly caring and supportive towards fellow activists and to make personal sacrifices on behalf of the movement. Others were exceptionally articulate and acted frequently as spokespeople for the movement. These latter tended to convey particularly ordered representations of their lives, and to offer up unequivocal accounts of activism.

[98] Concerning the ethical implications of these disclosures, both men had reported these incidents to the justice system prior to talking to me, so I did not feel I had a duty of care to report either.

2001; Crossley 2004; Everman 2005). Attending to the senses was a vital aspect of fieldwork, since activists perceive it as crucial to support and intersubjectivity.

In time I became so accustomed to activists' accounts of trauma and maltreatment that I ceased to be shocked. Nevertheless, bearing witness to such reports places the anthropologist in an invidious position; while one may seek to represent and do full justice to interlocutors' experiences of suffering, it is important to avoid sensationalism or exoticisation. I tried to turn my attention away from 'narratives of suffering', (Robbins 2013; Laidlaw 2014) in which people are "defined by their deprivation more than their subjectivity or humanity" (Mittermaier 2013; 13) by addressing what matters to activists in the context of their daily lives. During some of these difficult conversations, I also pondered how, "in much qualitative study about human extremes, participants may see research as a vehicle for giving testimony about injustices" (Boyden 2004; 242). This raised questions initially about what kind of information (or data) activists would want to share with me. As well, I sometimes got the impression that people were telling me what they thought I wanted to hear; they would often check with me whether I thought they had 'got it right'.[99]

When working with so-called 'vulnerable participants',[100] there is an expectation that the researcher will work to establish trust over time and in different contexts, thus making it possible to ask sensitive questions. However, I had the opposite problem. My interlocutors divulged incredibly personal information from the outset. Indeed, I sometimes tried to discourage them from focusing on their experiences of hardship, particularly those involving harsh or unjust treatment by mental-health professionals. Their tendency to focus on suffering may have been due to assumptions about the motives behind my research (if, for example, I identified as a 'survivor researcher'). I had to constantly reassure people that *all* aspects of their lives were interesting to me, including things that might seem banal. I pointed out that anything that was relevant or significant for them *was* also important for me.

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[99] Jupp (2020) details a similar phenomenon in her research with (mainly) women discussing the closure of children centres in England. She notes high levels of reflexivity around the *telling* of these stories, as well as particular *ways of telling them*. She argues that the process of telling stories is in itself an act of citizenship; their reception mattering 'politically and personally' (non-paginated). By the same token, the women saw contributing to her research as a political act.

[100] As defined by University of Kent (2021) and other ethical guidelines (c.f. ESRC 2015)

As it happened, I did not feel prepared for, nor had I anticipated, such immediate disclosure of deeply personal experiences. I was awed by interlocutors' honesty, but also intimidated as it felt as though I was being given great responsibility. I did not always feel that I had had time to get to know people well enough to be able to contextualise what they were saying. I worried that there had not been enough time to process and adjust to my relationships with interlocutors, especially at the beginning of fieldwork. My concern centred on knowing relatively little about activists outside of the 'activist' context and yet also being party to exceptionally sensitive personal information about them. Initially this felt like an imbalance.

Another concern was that mental-health activists are used to being 'observed' and this frequently turned out to be more of a hindrance than an aid to my fieldwork. Most feel the negative impact of mental-health professionals and researchers scrutinising their lives.[101] In their efforts to diagnose illness, clinicians routinely collect information about the attitudes and behaviour of patients in clinical settings and elsewhere.[102] There are also many other ways in which interlocutors are observed and tracked, including by friends, family, GPs, the Government and welfare agencies, the latter because many depend on benefits and must regularly prove their eligibility to receive them. It is perhaps unsurprising that, as a consequence, interlocutors' attitudes towards surveillance are highly ambivalent.

That said, scrutiny by researchers and journalists is sometimes perceived to be a 'good' thing because it permits the sharing of information that may help further activists' cause. But it is also understood to be stigmatising and as imposing a hierarchy between observer and observed, which can greatly disadvantage the latter. Thus, to avoid replicating these difficulties, I did not take field notes, whether during participant observation or interviews. Instead, I either obtained permission to record data on my mobile phone or wrote notes up subsequently.[103] Even though this strategy meant that I was not always able to detail

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[101] For an anthropological perspective on the issue of trust and scrutinization in health, please see Moutsou (2011).

[102] See Foucault (1963) for a detailed elaboration of this phenomenon.

[103] For more about interlocutors' deep discomfort with bureaucracy and being written about, see chapter 3. I found that recording was much more accepted, possibly because interlocutors' words are documented verbatim and there is less room for interpretation than with notetaking. The recorder also served as a useful reminder to informants of the nature of my task. I did not record sessions if there was any possibility that it might cause my interlocutors' disquiet. I always ask if anyone minded being recorded before group sessions or interviews began and made participants aware the machine could be switched off at any time. I transferred recorded audio data to a password-protected University of Kent drive.

specific interactions, not taking notes had certain advantages, allowing me to listen deeply and engage with my surroundings, whilst fully immersing myself in daily activities. It allowed me to observe body language and other social dynamics, especially the more subtle, embodied aspects of mutuality, such as tones of voice, touch, gestures, etc. Thus, I was able to gather rich data on the embodied aspects of fieldwork, rather than be overly concerned with narrative and verbal content around mental health activism, which has in any case been extensively documented in sociology and social work already (see for e.g., Crossley and Crossley 2001; Crossley 1998; 1999; 2002; 2004; 2005; 2006; Dillon 2010; Edgley et al. 2012; Spandler 2014). The soundness of this decision was reinforced one day when I jotted down some personal logistical notes in my diary whilst relaxing in a café with three interlocutors. One of them glanced nervously at my diary and asked what I was writing about and whether it concerned her.

Similarly, although I supplemented participant observation with interviews, these were mainly semi-structured. I chose this approach partly because I hoped that interlocutors would not confuse these instruments with formal bureaucratic procedures. Semi-structured interviews allowed me to ask specific questions whilst enabling interviewees primarily to shape the interview. This applies especially to activists, many of whom are made to fill out Improving Access to Psychological Therapies (IAPT)[104] and wellbeing questionnaires, which they disparage for oversimplifying complex personal experiences, being repetitive and meaningless and generally making them feel misunderstood and undervalued. Armstrong (2017) has written eloquently on the reductive and oppressive effects of clinical language, which, he maintains, serves to obscure and oppress people's lived realities. I sought to avoid, as best as I could, any processes that could be interpreted as mirroring dominant power relations, including written consent forms, using verbal consent instead.

Further, as indicated, one of my findings is that activists resist narrative coherence as part of a political strategy to live 'otherwise'. I sensed that few interlocutors wanted to put their experiences into narratives for my purposes, something they have done (or have been made to do) numerous times during therapy. They showed little interest in describing their experiences to others simply for the information to be used time again by nameless

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[104] For an extensive anthropological discussion of the pervasiveness and impact of IAPT in the UK's mental-health settings see Bruun (2019).

systems and people working in those systems. It follows that much of what made sense in fieldwork was conveyed to me without words. Beatty puts it succinctly,

> Probably most anthropologists would find it hard to draw a sharp line between what they learned by talking to people and what they absorbed through taking part. The current emphasis on dialogue, with its ethnocentric bias towards the tête-à-tête, claims to put all its cards on the table but actually masks the essentially mysterious process of coming to understand (or thinking one understands) what is going on in another culture and the very real part played by personal, sometimes unarticulated, experience in this process (Beatty 1999; 76).

Interviews

Given the rich discussions I was able to have with interlocutors throughout fieldwork, I did not feel the need to conduct many individual interviews. Moreover, I was concerned that interviews might somehow feel forced and unwelcome. For reasons I will touch on later, it also seemed that narratives centring on individuals would not necessarily be the preferred option in a context where collective histories and collective activities are emphasised. The idea that people speak with one collective voice (but not as a monolith) is important for mental-health activists and is echoed in activist literatures (e.g., Mills and Hart 2021).[105] Activists 'push back' against the notion that mental health service-survivor knowledge can be located in the individual. As one interlocutor put it, "Our narratives make one quilt, we are many voices who make up one voice" (Janet; 2019). Thus, I felt that too much emphasis on individual stories would be inappropriate. Further, I witnessed many debates about the emotional upheaval many go through when describing their experiences, especially when they believe they are doing so for the sake of others (or for the 'wrong' kinds of reasons) rather than for themselves. Moreover, some activists prefer to focus on their activities in the present instead of dwelling on the past.

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[105] Other studies of intentional communities have similar findings. Byrne (2010), for example, gave up conducting interviews at Brazier's Park, finding that the constant conversation and debate that was a part of the community culture already provided substantial information for her ethnography. Perhaps more importantly, the constant discussion among community members left participants with little energy for one-to-one interviews. Additionally, many activists value direct involvement in research, most likely because they understand that the co-creation of knowledge can be empowering (Faulkner and Layzell 2000) and valuing the testimony of people with mental health diagnoses challenges any assumptions about them as being 'unreliable' respondents (Martin 2001; Rose 2015).

In the end I only did nine interviews and on all of these occasions used locations chosen by my interlocutors, most often cafes. Initially I was surprised by this choice because we generally sat close to other customers and could be overheard. But I soon realised that talking openly in a public space was a conscious decision taken to avoid hiding or feeling ashamed of mental ill-health and associated experiences. For instance, interlocutors did not lower their voices when talking about topics like being sectioned. Interviews typically lasted between two to four hours, and I later transcribed the recordings. My intention was to give interlocutors the opportunity to choose what they wanted to speak about, so I tried to ask broad, open questions, such as, 'how did you become involved/why did you become interested in activism?' Some interviews took on the characteristics of life histories and resulted in lengthy anecdotes. Most were conducted in the latter three months of fieldwork, giving me a greater understanding of interlocutor's personal feelings about activism, and the experiences that have influenced them. In some cases, interviews enabled interlocutors to discuss topics they were wary of addressing in more public settings. For example, they gave me insight into some of my interlocutors' more personal feelings about their relationships with other activists, including instances of conflicts.

1.3 The importance of positionality in fieldwork with Service Evaders and Survivors

Politics and identity

The ethnographer heavily influences the outcome of the research, as highlighted by Mauthner and Doucet, "we are confronted with ourselves and with our own central role in shaping the outcome" (1998; 122). How I was perceived and how I presented myself in the field mattered a great deal in terms of the degree to which I was trusted by my interlocutors, the access they gave me to different conversations and spaces and my interpretation of the ethnographic evidence. Almost regardless of how I introduced myself, or explained my presence at groups or events, there remained implicit assumptions about the purpose of my research. I had to contend with and negotiate these assumptions throughout fieldwork.

Some of my participants were aware of Goffman's ethnography, *Asylum* (1961). Pretending to be insane, Sociologist Goffman was sectioned covertly and checked into a

mental hospital. His work has left some interlocutors feeling ambivalent about ethnographic research. I was told that it was dishonest of him to conduct ethnography in secret, without obtaining informed consent. There were concerns about him having an unchallenged and privileged critical stance. But Goffman's work revealed asylums to be places of harsh governance, coercion and control and many greatly appreciated his having exposed these injustices. Interlocutors seemed to associate my work with Goffman's. I was positioned as being against both institutional therapies and psychiatry, with the assumption that I too was committed to furthering activists' cause. Thus, I was asked several times, with some eagerness, whether I also planned to go 'undercover' in mental-health hospitals to unmask their practices.

As it happened, not undertaking fieldwork in mental-healthcare settings, or even observing or interviewing mental-health professionals, was an explicit choice as I was concerned that to do so would undermine my relationship with activists. In making this decision I was influenced by Myers (2015), who discusses what she calls the threat of 'dignity violation' when researching in mental healthcare settings, such as hospitals. Her argument is that in such settings researchers end up mirroring the dynamics of health professionals. She notes that dignity violation is "more likely to occur in non-egalitarian situations where one actor was vulnerable (in this case, the patient) and the other subject to antipathy (e.g., staff)" (2015; 135). People with social power (i.e. social status, capital, or authority) are generally perceived by activists to be less trustworthy, or even threatening. I found this when I accompanied a psychiatrist to a public event and was heavily censured for doing so by the activist community. I was also criticised for associating with an anthropologist who was known to be sympathetic towards psychiatry. I did not want to be seen as either a mental-health professional, or an ally to professionals; nor did I wish to be suspected of colluding with them. So, in the same way that anthropologists Clifford and Hildred Geertz infamously fled the police during a Balinese cock fight raid in 1973, I learnt to avoid psychiatrists to prove to interlocutors that I was trustworthy.[106]

Many activists seemed think that I was myself a service survivor, the assumption being that researchers only become interested in them and their cause when they share similar experiences. I was frequently asked what my experience of mental distress was and what

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[106] I did occasionally engage with professionals at conferences and other events but overall chose to have minimal interaction with them, or indeed any other individuals or groups that were perceived by my interlocutors to be in positions of power– even those who run service-user led discussion groups.

I identified as—service-user, survivor, evader, (or occasionally mental-health practitioner). For example, I was asked why I had not joined the Survivor Research Group, which has an explicit manifesto committed to positioning survivors as experts in their own lived experience. 'Service-user researchers', or academics who identify as service-users, are quite prolific in mental-health research. Their experience of mental health provision informs their research and structures their relationships in the field in such a way as to serve the goals of activism. Commonly thought of as 'critical friends', the group is held in contrast to clinicians and 'other' non-survivor researchers.

Gluck (2012) and Juris (2008) have written about the significance of protesting and embodying space as an activist practice, the implication being that simply by being in a place the researcher is somehow complicit in supporting the activist cause. Equally, as other anthropologists of social movements have pointed out, those who are *not* deemed to be fully on board with activist causes may be treated with suspicion or regarded as a marginal figure (Pink 2008; Juris 2008; Thomassen 2012). When it came to settling on how to identify myself, the stakes were high, as at times my identity was a cause of contestation, such that several activists argued about it openly.[107] Activists often hold polarised views about what it means to be a clinician and what it means to be a service-user. Insofar as clinicians invariably engage in surveillance of one form or another as part of the treatment process, many of my interlocutors are extremely ambivalent about this category. Given the significance activists award to the identities of user, survivor, evader and practitioner, and the diverse meanings they give to these roles, I struggled to reconcile their varied understandings and to settle on an explanation as to my role and purpose that was both coherent and acceptable to research participants.[108]

Since I did not initially identify as either a service-user researcher or a mental-health practitioner it was often difficult for people to understand my position. I therefore decided to self-identify differently in different contexts, depending on who I was with, how comfortable I felt with my role and what seemed relevant to disclose. Although this

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[107] This was partly a reflection of diverse understandings of what different identities mean. As explained in the introduction, identity is important in the field of mental health activism. As Mills (pers. comm.; 2021) explains, discourses in mental health activism often focus around polyphony – 'survivor' can mean anything—survivor of services, of distress, or of a particular treatment (such as ECT) or treatment model, for example psychiatry. She notes generational divides between people who self-define as users (younger groups and people of colour do not identify that way) and people do not perceive what they do as activism. In my research, interlocutors did not always describe themselves as 'activists'.

[108] The polarisation of clinicians and patients for example reveals a particular tension between the kind of moral certitude activists hold about some things, in contrast to their flexibility regarding others.

appeared to be the most practical strategy, it was quite confusing for me, not least because as I gained more understanding and knowledge of what the different identities meant to different people and groups, I realised I needed to make further adjustments. For example, at the beginning of fieldwork I mainly chose to describe myself as a 'PhD student' and as I grew in confidence, changed this to 'an anthropologist'. But as I began to share more of my personal experience and came to respect and understand the importance of different activist identities, I began to align more with the identity of a 'service-user researcher' or even 'service evader'. [109] Eventually, as I became a familiar face in activist events and got to know participants better, questions regarding my identity ceased. I began to be invited into certain spaces and conversations, some of which were closed to many other members.[110] I was given key roles in campaign strategizing, added to private social media groups, and I took this as an important indicator of the level of trust I had gained.

Regardless of how I self-identified, many interlocutors were resistant to academic research in general. Concerns about exploitation of survivor voices and distress caused by researchers is covered extensively in activist media, including in survivor blogs, such as 'an open letter to the professional class' (anon; 2020).[111] These postings make clear that many activists feel used by researchers, who they perceived to be 'selling' activists stories for their own personal gain – whether for furthering their careers or for profit. In line with these concerns, a couple of people asked me whether I had already identified a publisher for 'my book'.

Gender and other characteristics in fieldwork

My gender had a major influence on both my field experiences and my findings. In general, women undertake much of the social and emotional work of mental-health activism, and there seems an implicit assumption that women are more efficient caregivers. Such assumptions felt present in many of my interactions in the field—as echoed in the things people said to me and occasionally, their behaviour towards me. Across the three activist groups I visited most frequently and during all the events I attended, there appeared to be

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[109] For enlightening discussions on how anthropologists may attempt to move away from a researcher-based identities whilst also establishing informed consent see (Fluehr-Lobban 2003; Silverman 2003; Macdonald 2010)

[110] It is rare for mental-health activists to exclude others and happened only twice while I was in the field – once because a touring activist requested a small audience as they felt tired from travelling.

[111] See also (Beresford 2002; Carr 2019; Faulkner 2021).

slightly fewer women present than men. Aside from the facilitators, men were also more vocal in meetings than were women and they tended to occupy the most comfortable front-facing seats. However, women took on most of the logistical and administrative work, such as disseminating information about events and other activities.

Assumptions were often made about me, and these would sometimes create a difficult dynamic in my exchanges with interlocutors. There were two contrasting tropes. On the one hand, emphasis was given to my seeming vulnerability as a woman. For example, it was frequently thought that I needed to be protected in public settings and chaperoned when attending events or meeting people. Eyebrows would often be raised when I explained that I had cycled across London to attend meetings or walked alone across a particularly 'dodgy' London park. On the other hand, more than one person commented on how young, healthy and vigorous I looked and quite a few participants appeared to see me as someone they could confide in or turn to for support. This situation could be quite demanding, physically and emotionally, as when interlocutors expected me to remain with them for hours, sometimes until late in the night. I frequently left these encounters feeling used and burnt out. In the hope of lessening the demands on me, I eventually disclosed my struggles with a chronic health condition that at times causes acute pain. However, unfortunately, this strategy was not very successful.[112] I never quite managed to fully resolve the expectations and ambiguities underpinning my relationships in the field. That said, near the end of fieldwork I did comment in my field notes that I felt I had finally established a few genuinely 'reciprocal' relationships.

What distinguished me most from my interlocutors was that I had an occupation as a student; this caused mixed reactions. The majority of activists are on benefits, and many have not worked for years; some have never worked. While many see learning and research as having inherent value, others perceive education to be a waste of time. Worse still, some regard it as an elitist activity only open to those who have no real concerns or responsibilities. Equally, even though some people were impressed that I had set a whole year aside to study with them, others remarked that a year was not long enough. Some

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[112] Occasionally, after explaining multiple times that I was very cold/hungry/needed the toilet/a rest, I would have to leave in the middle of a conversation. More than once, if someone was talking to me, or I was in a position of responsibility (e.g., video recording, or holding a sign during a protest), my requests to end a conversation were ignored. This was in contrast to other types of activism and organising I have engaged in, wherein a conscious effort is made to carefully divide tasks between participants and both rest and breaks are seen as necessary and acknowledged.

interlocutors were impressed when I explained that I received funding to undertake my research, although this was also a source of suspicion. At one meeting, a man yelled at me, "Who funds you love?" imagining—I assume—that it was 'big pharma,' or another source, such as the Wellcome Trust, that activists do not trust. On the other hand, several other interlocutors expressed the view that as a student engaged in documenting and supporting the activist cause I would somehow be able to 'pay back' an imaginary debt that was owed to them by the state (see also Han 2012).

Whereas most activists live in precarious accommodation and lack a regular income, I had a studentship and was able to rent stable accommodation. Even so, some interlocutors seemed to regard me as a poor student just starting out in life, taking it to be their duty to be kind to me. For example, they would caution, or even warn, me against particular individuals or groups. At times I felt overprotected. My age also put me in a slightly liminal position because I am older than most interlocutor's children (those who had children), but younger than most of my interlocutors. This meant that I sometimes felt as though I occupied a position somewhere between daughter and peer.[113]

Equally, several of the activists who recounted difficult life events to me noted in surprise that I did not seem easily shocked. And one person described me as 'very open minded'. I can only assume that their surprise was at least partly due to their expectation that I had led a protected life and would therefore find these disclosures upsetting. These kinds of responses made it clear that, because of my class, age and education and also, sometimes, my gender, my position among activists was at times quite ambiguous. These characteristics either distinguished me from the majority of my interlocutors or challenged their expectations around appropriate behaviour. I often felt respected, and yet it was also as though my presence confused social categories and understandings. Thus, my experience in the field resonated closely with the experience of other female anthropologists who, for example, assume male roles because they do not adhere to conventional gender expectations (see for example Warren and Hackney 2011).

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[113] I was aware that my youth might disrupt my relationships, knowing from my MSc research that activists were likely to be quite a bit older than me. Occasionally participants would be particularly maternal or paternal towards me, though they would often complain or confide in me about their difficult teenage children, laughing as though my youth gave me special insight into their children's worlds.

1.4 Research ethics

Informed consent

This section explores my approach to and the challenges around informed consent. Some anthropologists question the universal applicability of informed consent. For example, Alexiades and Peluso point out that, "The consent process is inevitably tied to respondent's *expectations* about what research entails, including participants' understandings of its *purpose*" (Alexiades and Peluso 2002; 222). I soon learnt that activists' understandings of the purpose of my research were heavily influenced by their involvement in previous investigations, as well as anxieties generated by the prejudicial attitudes towards people with mental-health diagnoses in the media and among the general public. Given these circumstances, the nature of my enquiry and the precarious circumstances of my interlocutors, informed consent was an ongoing process that persisted throughout my time in the field.

As Utas (2004:211) highlights, in turbulent contexts, ethnographers risk being barred by interlocutors at any time. Many interlocutors live in a perpetual state of anxiety, and this repeatedly threatened to undermine their confidence in me. I therefore needed to regularly reiterate the purpose of my research and obtain consent (Peluso & Alexiades 2002). Doing this ensured that interlocutors would have a consistent understanding as to what my research was about. I explained my study to all of the groups and individuals I interacted with, asking them whether they would agree to be involved, seeking their permission to record sessions, and revisiting the process before, during and after all sessions. At group meetings I would often leave the room so that participants could discuss and make decisions regarding consent without me being present. Despite investing quite a bit of time in obtaining verbal consent, I felt it was also important to have something in writing.[114] About a month into fieldwork I sent an introductory email to the three groups I was most engaged with, as well as shorter emails to other groups I was considering studying. The email was simple and explained who I was and what I was researching. It gave my mobile phone number and email address, permitting people to contact me directly. I also posted messages about the research on Facebook groups, Slack and googlegroups.

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[114] This decision was taken with awareness of the variety of accessibility and neurodiversity experiences among mental-health activists and the understanding that it might help some to have information in writing as well as verbally. Faulkner (2004) also advocates for this approach and points out that interlocutors might need significant periods of time in order to consider their involvement in research.

Given the sensationalist coverage of people with psychiatric diagnoses in both the British media and public discourse, suspicions around misrepresentation and exploitation are rife among activists; I soon learnt that they also have qualms about research. Shortly after posting the consent messages, a long thread—a discussion between members of the SAP googlegroups—appeared in my inbox. In one posting someone asked, "What the fuck is this research going to do?" One replied "researchers never understand" and another said, "why would I go out of my way to talk to her?"[115] I was not sure whether I had been included in this discussion intentionally, but it alerted me to the misgivings many activists have about researchers and clarified their concerns about being over-researched and scrutinised.

Suspicion and mistrust were particularly evident in the first few months of fieldwork and comments made about me at this point shed light on activists' fears. I fielded many questions about the aims of my research, such as, 'What do you identify as (i.e., mad, a survivor, a service-user)?' 'Why are you here?' 'Are you going to expose the movement?' I tried to explain that ethnography does not necessarily entail specific aims, but this response was considered too vague, doing little to assuage activists' apprehension and causing some confusion.

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[115] Out of these three interlocutors, two did not participate in activism in-person during my time in the field but remained very active online. The third ended up becoming one of my key interlocutors. In the end, they all spoke to me and welcomed my presence in the field.

Figure 1 The difficulty of trying to explain why I was conducting ethnography

I met up with one interlocutor, Will, early on, specifically to answer his questions. Will is a young man in his late twenties who sports a large black coat. He dislikes conflict, is unusually gentle and strives to find common ground between people. We sat in McDonald's for hours as he questioned me about my politics, background and views about the mental-health activism. He also wanted to know how I planned to use the information I was collecting, and whether I intended to support, or 'expose', the activist cause. I found myself explaining that I would do *neither*—a response that he seemed to find unsatisfactory. Even when I felt I had established a level of acceptance, uncomfortable references about my research continued to be made. For example, a seemingly light-hearted exchange with one interlocutor (who eventually became a key informant) on Messenger went as follows;

Figure 2 Conversation with interlocutor on Messenger

This individual constantly referred to the fact that I was doing research and often made fun of me. I came to see this as his way of highlighting the power dynamic inherent to the researcher; researched relationship. As Surie Von Czechowski (2019; non-paginated) points out, rather than "a mere tool to lay the foundations for interpersonal trust in ethnographic encounters," jokes and laughter can reveal vulnerability and difference, whilst also gesturing toward the possibility of respect and recognition.

With consent an ongoing process, this meant that I needed to work hard throughout fieldwork to sustain interlocutors' trust in me. For example, I would give them the opportunity to cross question me whenever they wished to, shared findings from my previous research and recounted my previous experiences with 'mad activism' and activists' mental distress at Occupy. I outlined the University's ethical code and explained that I was accountable to the institution for upholding its ethical standards. It helped that I had befriended a well-known and respected activist during my MSc research at Occupy. Particularly in the first weeks of fieldwork, I met with many interlocutors individually to allay their concerns by discussing my work in detail. For example, I arranged to meet Mike one day, a highly intelligent, astute man in his late thirties, to ask if I could participate in peer support-group sessions he runs in the East End. He frowned as he told me that the group had had researchers sit in on sessions before and that it can be "awkward". Yet, he went on to clarify that group members generally like outsiders to take an interest in them. Mike

asked me what kind of questions I might ask; then, without allowing me to respond, he quickly added;

> Well, you're not going to ask about people's personal mental health are you… so it won't upset people, like others have. We've had people come along in the past, asking personal questions then leave. And people feel used up and left. You are going to ask about support and alternatives, right?

Other interlocutors also asked whether I planned to focus on accounts of 'mental illness and distress' or 'activism, alternatives', their concern being that I should, 'look at them as "people" and not illnesses'. Similarly, some queried whether I was I going to, 'see what people did and make my own analysis about them' –or was I going to ask about what mattered to *them*?

These questions made me nervous about addressing mental-health issues directly and I grappled with how best to frame my enquiries and which questions to ask throughout my research. I tried at all points to strike a balance between activists' ethos and preference for self-representation and my own understanding of robust anthropological enquiry, which involves looking beyond what people *want* you to know. Thus, I generally focused on interlocutors' daily lives, relationships, and involvement in activism, rather than the specific character of their distress; usually, I only tackled this topic when it was introduced by interlocutors themselves.

It gradually emerged that while people did not openly resent my presence at meetings, they found ways of expressing their discomfort with my research role. I came to understand this later as an inherent part of disclosive freedom (see chapter 6)—again this circumstance reinforcing the need to obtain consent continuously, throughout fieldwork. That some interlocutors expressed disquiet about my work remains a concern for me, making choices about writing difficult, since I am very aware that this thesis will not please everyone.

The Politics of anonymity

To protect my interlocutors, all names of individuals and places mentioned in this thesis have been anonymised using pseudonyms and any characteristics that might facilitate

their identification removed. Nevertheless, anonymity was not necessarily what my interlocutors sought, which posed something of an ethical dilemma for me. From the outset, several interlocutors expressed a wish to be named in the thesis, in the hope and expectation that this would enable them to gain public recognition and acknowledgment of the legitimacy of their concerns about mental-health provision. This approach aligns with that taken by other studies of mental-health activism (i.e., Beresford 2014; Faulkner 2017; Rose 2017). But, as my fieldwork progressed and I became aware of the complex political and interpersonal dynamics among interlocutors, I grew increasingly concerned that revealing their identities could have unforeseen adverse repercussions for them, as well as for the wider activist population. For example, after leaving the field I became aware that incidents that are normalised in mental-health activist circles can appear shocking, or even deviant, to those outside this context (Lee and Renzetti 1993). As well, I was concerned about disclosing interlocutor's identities given that people with diagnoses of severe and enduring mental illness are commonly subject to fear, stigma and misunderstanding. I realised that publishing interlocutors' names might incur shame or embarrassment since their histories risked being misunderstood if taken out of context (Liamputtong 2007). This concern was further heightened following my return to the University when, during my first postgraduate writing seminar, I was accused by my peers of being a rape apologist—on the grounds that I had listened to a rape confession. On a different occasion, during a conference, I was taken to one side by a senior professor who told me not to discuss 'shit', as "people don't want to hear about that kind of thing".[116] These experiences made me realise that my role as listener and the intense relationships I had had with some interlocutors, might be judged inappropriate by outsiders and even my peers.

Shaming of anthropologists who research participants in informal or criminal economies is not unheard of. Waldram (2012), who worked with sex offenders, noted that he has been accused of being an apologist and supporter of evil, and a sexual offender himself. By giving voice to offenders, he has also been vilified as a silencer of victims. Kirby and Corzine (1981) argue that in this phenomenon researchers come to share the stigma experienced by the subjects they study. Sanders and West (2003; 14) argue that these attributions are evidence of an 'empathy gap', wherein a failure to sympathise with certain

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[116] In this instance, I was recounting the case of one interlocutor who has double incontinence due to reactions between her different medications. As part of speaking out, she satirically refers to herself as a 'psychiatric shitter' and is very vocal about the burden and expense of using incontinence pads. She is open about this issue and feels she should not be shamed into concealing it.

research topics/ subjects (particularly those perceived to be 'closer to home') leads observers to disagree with, belittle, or even demonise their views, experiences, and conduct. In my view, the shaming of researchers who study stigmatised groups works against the ethos underpinning the anthropological endeavour, in which the representation of emic perspectives is a core principle. I sincerely hope that my thesis does justice to the telling of these difficult accounts and does so in a way that makes clear that I neither judge nor condone the actions of my interlocutors.

Reciprocity

One of the central ethical challenges of ethnographic enquiry is the potential for it to be experienced and perceived by interlocutors as an extractive process. It is an important ethical imperative to try and ensure that research is, as far as possible, a reciprocal exchange between researchers and researched. Research reciprocity includes emphasising the potential benefits of research for interlocutors, this having been held up as an ideal in anthropological work. For example, in her fieldwork with English travellers Okely (2010) writes about the potential for fieldwork to be defined by her interlocutors as pseudo-therapeutic. She describes how they joked about her listening to their woes, whilst also reflecting that this enabled them to process difficult experiences in the presence of someone they trusted. Similarly, many of the imprisoned inmates studied by Waldram (2012) reported that his research provided a valuable setting in which they could speak out without being challenged.

My research was conducted in places chosen by interlocutors, where they knew they could gather and speak frankly about sensitive subjects without fear of stigmatisation or recrimination. A number of my interlocutors told me that my research had provided them with an important space for them to critically reflect. Several also explained how meaningful they found it to have someone who was neither close to them nor had 'heard it all before' listen to their accounts. The act of being present and listening is very important; it is not apolitical, particularly in contexts where both people and their actions are heavily stigmatised. I feel confident that interlocutors were willing to participate in the research because I was happy to hear them out while others would not. Even if I had heard many of their narratives before, I did not mind hearing them again. I also agreed to present my initial findings to my interlocutors via papers, workshops discussions and

conference presentations, some of which were delivered during fieldwork.[117] Feedback from these events suggests that my findings have been useful to interlocutors, for example by identifying the most effective way of lobbying for social centres to remain open following the Covid-19 pandemic, Brexit and the associated cost-of-living crisis.

Partly due to my extensive networking among activist groups and individuals, and the time I had available to conduct fieldwork, participants considered me to be in a position of knowledge. This enabled me to reciprocate the generosity they showed me by mediating between groups and individuals. I would be asked about what other groups were doing, how various individuals were getting on, and what events were taking place. I shared knowledge when I felt it might be relevant and useful, for example informing interlocutors about events such as deaths, funerals, and protests. For the most part, I refrained from providing information about treatment or healing options, partly because I was not party to interlocutors' diagnoses and am not trained as a mental-health practitioner. I was also concerned that I might influence interlocutors' decisions, thereby undermining the research. However, on occasion, I did share information when asked questions that I perceived to be 'low risk', such as 'Does anyone know of any respite houses or crisis centres in the UK?' By assuming this role, I came to realise that communication between groups can be fragmented.[118]

I also tried to reciprocate interlocutors for the time they gave to my research by helping them with practical tasks. I proofread CVs, filled out benefits claims forms, commented on draft manifestos, took minutes at meetings and edited one man's memoir. I helped restore dilapidated buildings by fixing leaky pipes and fuse boxes and occasionally put people up in my rented house-share when they had accommodation difficulties. Aside from enabling me to build trust with research participants, supporting them with these tasks gave me an understanding of the bureaucratic burden they bear when claiming benefits (see chapter 3). It also afforded insight into how this burden constrains activists' lives, including the fears and insecurities it invokes around illiteracy.

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[117] I presented at a workshop held in a service-user café, an activist conference on 'Other Ways to Care' (both 2019) and more recently, at a lived experience/academic conference on Mental Health and Social Power (Cambridge, 2021).

[118] Knowledge exchange is highly valued. There are some efforts to connect networks and collate relevant information (such as the Survivor History Group webpage, or the FLL newsletter), but individuals have to actively seek this out.

Staying well in the field

Studying mental health can be challenging for the researcher, not just because listening to narratives of suffering can be very painful, but also because these narratives may address topics—such as maltreatment, domestic violence and coercion—which raise dilemmas around identifying an appropriate response. No amount of training could have prepared me for some of these challenges.[119]

Possibly the most difficult aspect of my work was finding a way to effectively balance the enormous sense of responsibility I felt towards interlocutors with establishing clear boundaries to these relationships. The latter was necessary for protecting my own wellbeing. It was particularly difficult to contain the desire to help interlocutors who were in distress, and I found it troubling not giving them money, nor allowing them to become too dependent on me. Some of these ethical conundrums also prevented me from seeking support from my family or friends, who were unaware of the daily struggles faced by my interlocutors. I had to take great care to protect myself emotionally in ways that occasionally conflicted with my ideals of what ethnography should entail. I ended up compartmentalising my life—for example, by taking a break during field meetings, or taking a day off after particularly difficult encounters (which happened regularly). Because of my expectations about 'true' ethnography as involving continuous presence in the field, I often felt quite conflicted during these breaks. Like Malinowski (1922) I felt I should be fully immersed in the field at all times.

The risk of suicide is ever-present among interlocutors. Thankfully, none of my interlocutors disclosed feelings of suicidal ideation to me directly, although the topic frequently came up in discussions. [120] Thus, existentially, the suicide or death of interlocutors was always a threat and I remained anxious throughout fieldwork that I might one day fail to respond to a cry for help in time. An associated concern was that, were this

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[119] I tried to prepare for this research in various ways by undertaking a 'Mental Health First Aid' course and a 'Secondary Trauma in Research' course (Oxford University) and by attending conferences on 'Safer Spaces' and peer support which align more with the type of support activists are familiar with.

[120] 'Suicidal ideation' is a term originated in the mental health professions and refers to explicit plans or thoughts about committing suicide. I do not personally adhere to such prescriptive or rigid understandings about suicide or talk around it as intentional or unintentional, but I use it here to differentiate talk about actively planning to commit suicide and other kinds of talk. Mostly, I chose to use my personal judgement –i.e. if I felt someone to be suicidal but they had not expressed it to me then I would have sought help from other activists, equally, many people talk about plans, but it is quite clear that they have no intention of carrying these out – sadly in my personal experience, it is almost always the people who have not spoken about such things at all who end up actually committing suicide.

to happen, I would feel complicit in, or responsible for, a death. This anxiety made it very difficult to maintain the emotional distance from interlocutors that I needed, even when I was away from the field. With hindsight, I realise that a few simple measures might have helped. For example, it was not unusual to receive extremely intense personal texts or emails from interlocutors well into the night– these could include cries for help from people in great distress. If I were to undertake fieldwork again, I would use a separate telephone to communicate with interlocutors.

Throughout my time in the field, I felt I should seek the same kinds of emotional support that my interlocutors access, as well as use the methods they use, such as speaking openly about personal distress in group contexts. This proved difficult, as it took me a long time to understand that support is not just about speaking, or direct intervention, but also subtle interactions such as listening (chapter 5). Also, I found that, even though personal disclosure was likely to increase activists' trust in me, I was not able to 'speak out' about my personal life as freely as they do. I did talk in private to a few people, but never felt able to speak openly in public as this made me feel vulnerable, including by exposing me to the risk of accusations around homophobia, classism, activist 'voyeurism' and the like. Avoiding public personal disclosure did not feel ideal methodologically; nor did it resonate with what I thought fieldwork should be. However, sometimes I had to prioritise my emotional wellbeing over methodological exactitude, not least because this ensured that my interactions with interlocutors felt balanced.

Whilst preparing for fieldwork, I encountered frequent claims in the anthropological and other literatures that individuals experiencing mental distress automatically classify as vulnerable persons and that researchers must adjust their research practices accordingly (c.f. University of Kent 2021; ASA 2020; ESRC 2015). Biomedical ethics indicate that this means knowing when to leave an individual out of the research process, whether due to poor mental health or some kind of incapacity.[121] However, this approach would have been entirely inappropriate in a context where biomedical framings of mental distress trigger feelings of powerlessness and despair among participants. Given the specific

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[121] Within social and medical anthropology there are diverse views about the ethics of interviewing those referred to as 'vulnerable' people (in this case people who have been diagnosed with mental disorders), especially when the researcher does not have formal training in or much experience of the management of mental distress. Many medical anthropologists with health backgrounds adhere to medical codes of ethics, which take a bio-psychological perspective on mental health, stating that one must be trained to deal with a person diagnosed as mentally ill. 'Capacity' refers to the Mental Capacity Act 2005 - see chapter 2.

context of my research, I decided that it would be more appropriate to agree with my interlocutors which ethical principles to apply. I also used my own judgement and occasionally referred to my supervisors (both medical anthropologists) for advice. More often than not, activists are proactive, functional people who have spent a lifetime learning how to cope with life's difficulties and do not necessarily fit easily into the category of 'vulnerable people'. Nor do assumptions about what 'vulnerability' entails apply simply because activists experience mental distress. In Mad Studies scholarship, there is widespread acknowledgement that people who are mentally distressed do not need to be protected from experiences that they already live with daily. As Wilson puts it; "Activists do not shy away from hurt, suffering, even if they wanted to… They live alongside it every day" (Wilson 2020; non-paginated). Indeed, I argue that it is through their vulnerabilities that activists have become so clear, outspoken and resilient to the challenges that they face.

Luckily, due to activists' commitment to mutuality and collective modes of healing and support, I generally felt a devolved sense of responsibility when interlocutors were in acute distress. Sustaining people in such situations was almost always a group effort. However, at one point I was meeting regularly with an interlocutor who was evidently in distress; no one else was present on these occasions, nor was he engaging with many others. In this case, with his permission, I contacted someone he was close to and let that person know about his state of mind. Had I informed mental-health service providers about his situation, this would have been perceived as a betrayal of trust as well as my interlocutors' ethical principles, which would, in turn, have brought my fieldwork to an end.[122] Such action would also have violated my own anthropological code of ethics to never harm my interlocutors. Thus, I followed Butler's (2016; 2020) and other feminist scholars' (e.g., de la Bellacasa 2017) understanding of 'vulnerability'. They argue that it is not helpful to think of vulnerability as being inherent to particular conditions or people, further suggesting that 'we are all vulnerable'--in the sense that it is situations, conditions and relationships which shape our susceptibilities.

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[122] This assumption is drawn from the many interlocutors who talked openly about the sense of betrayal they felt when friends or family informed clinicians about their condition and were thus complicit in their being sectioned. My approach is also informed by the adverse reactions to sectioning among members of the Occupy camp in 2012.

1.5 Chapter conclusion

In this chapter I explored some of the key characteristics of my interlocutors and field sites and highlighted the opportunities and constraints that apply to this particular area of study. Among the more significant ethical constraints is the convention in medical and much social-science research of labelling people who experience mental distress as inherently 'vulnerable'. I highlighted the problematic assumptions intrinsic to this construction and explained why my research ethics were informed instead by the values and practices of mental-health activism.

I also outlined my research methods, noting their strengths and limitations, and summarised some of the challenges faced by researchers when studying mental-health activism. In doing so, I explained how many of the more important methodological choices I made were shaped by the specifics of my research topic. These include not taking notes during interactions with interlocutors, and concentrating on participative, collective and embodied aspects of fieldwork more than interviews. I discussed the problems of and entrenched inequities and assumptions inherent in the practice of terming interlocutors as 'vulnerable' participants. Possibly the most important methodological choice was to prioritise people's daily lives and movements across London, and to capture the diffuse nature of mental-health activism, over a more in-depth study of a single, 'stable', and fixed location; I have interpreted this as an 'assemblic' field, in line with Zigon's formulation (2015, 2018). Decisions such as these reflect and impact my broader theoretical framing and analysis, thereby contributing to critical phenomenological understandings of activist sociality, politics and mental distress.

Chapter 2: 'Treatment as Usual': Mental Healthcare in the UK

"In psychiatry, a diagnosis is the outcome of an inter-personal and eminently cultural interaction – a conversation – between patient and clinician. But one that is conditioned by a given bureaucratic system in which expert interpretations have to be matched to available treatments … it is more monologue than dialogue" (Mosse, forthcoming)

2.1 Chapter introduction

The World Health Organisation (WHO) maintains that mental illness is the single largest financial 'burden of health' (WHO 2016; c.f. DH 2011). Referring to the UK, the Mental Health Taskforce's 'Five Year Forward View for Mental Health' (2016), written for the NHS, states that 'one in four' people experience a mental illness at any one point in time. According to NHS statistics, the most common mental 'disorders' in the UK are neurotic conditions, such as stress, anxiety and depression, psychotic conditions being less common (Mental Health Foundation 2010).[123] However, despite the prevalence of mental distress nationally, physical health has long been a higher priority. The National Institute for Health and Care Excellence (NICE), argue that it is only very recently that [physical and mental health] have started to gain an equal footing in the health and social care landscape.[124] The shift was partly due to ex-Prime Minister David Cameron's push to increase recognition of the importance of mental health, an aim stated in the 'No Health without Mental Health' report (DH 2012), including by increasing funding to mental-health services. Current government rhetoric also focuses on mental health (e.g., DH 2017), with NHS England alleging that it gives 'greater priority and scrutiny to mental health services than ever before' (NHS; 2017). The push to more effectively address mental ill-health across the UK has resulted in a plethora of institutional and clinical initiatives, mostly

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[123] Psychosis statistics are contested. According to official figures around 0.7% of the English population experiences psychosis (PH 2016). However, research from the Hearing Voices Network (HVN) suggests that instances of psychosis among the general population are much higher, it is that they are not all distressing, and therefore tend to be underreported (HVN 2022). HVN claims that "somewhere between 3 and 10% of the population percentage hear voices, see visions, experience sensory moments, increasing to about 75% if one-off experiences like hearing someone call your name out loud are included" (Ibid; 2022).

[124] NICE is the national regulatory body for health and social care, renamed in 2005 to allow 'care' to be added.

involving the NHS—the country's main provider of public mental-healthcare. Since NHS provision provides the focus of much critique from mental-health activism in London, in this chapter I document some of the most significant institutional and clinical developments in the NHS over recent decades. I do not offer a comprehensive history of the institution, nor of its services, so much as highlight those features of its legal framework, polices and treatment pathways that affect activists most directly. The chapter is largely based on secondary sources, supplemented by insights I gained during fieldwork.

Virtually all of my interlocutors have had a formal mental-health diagnosis of one kind or another. Many experience what service-providers term 'severe' mental health problems; or in other words, 'psychotic' conditions, such as bipolar disorder and Schizophrenia. Others have been diagnosed with 'neurotic' conditions, for example obsessive compulsive disorder, anxiety or depression. Some have been given a dual diagnosis that includes both a mental-health and neurodevelopmental disorder, for instance Asperger's syndrome or Autism. Virtually all of my interlocutors have also been patients in the NHS, and many were still receiving treatment whist I was conducting fieldwork. A significant proportion of those who are NHS patients are in long-term or permanent treatment. Thus, NHS mental-health provision has a huge impact on activists' lives—this impact commonly being more negative than positive, which is largely what motivates activists to seek change.

I therefore begin the chapter by summarising the foundational principles of the NHS, noting the most serious challenges it has confronted over the years, and documenting the reform efforts of successive governments. In doing so, I endorse the argument by Armstrong (2017) and Turner et al. (2015) that the NHS has transitioned from its original foundation as a small-scale, trusted institution into an 'accountable service provider'—a process that, in the case of mental-healthcare at least, appears to regularly privilege institutional imperatives over patients' interests. I go on to trace what this trend implies for patients by exploring what 'Treatment as Usual' (TAU) constitutes in the context of NHS mental-health provision. The phrase 'Treatment as Usual' is used in healthcare to describe (bio)medically accepted, standardised clinical practice, as routed in scientific knowledge and principles. I provide an overview of NHS mental healthcare, briefly outlining its generic guidelines and codes of practice, as well as selected treatment pathways, focusing mainly on those experienced by my interlocutors. I address some of the controversies surrounding NHS mental healthcare, as articulated in the anthropological and critical health literatures and by my interlocutors. In particular, I make clear that activists reject

the values and practices embodied by TAU in NHS mental healthcare. This discussion provides vital context for understanding activists' ways of thinking, being, doing and relating in everyday life. I end the chapter by sketching out the background to mental-health activism and activist networks in London.

2.2 The changing structure of the NHS

The NHS and local government are the two main bodies in the UK responsible for public mental-health policy and services, so that healthcare is shaped by the norms, practices and reforms of these two institutions. The NHS was founded just after World War II, when it became clear that the healthcare available through municipal provision and charitable foundations did not meet growing national demand and was irregular in terms of approach and effectiveness. The primary consideration was not to increase provision so much as to standardise care quality across the UK, since it was assumed that this would improve health overall and therefore reduce demand for services. Developed in tandem with the Welfare State (Webster 2002), the NHS was designed to provide universal healthcare free of charge on the basis of 'clinical need' rather than 'ability to pay' (DH 2020). As Armstrong argues, "the NHS was based on principles of social solidarity, equity and efficiency […] care was to be free, comprehensive, and resources within the NHS would be pooled" (2017; 61). However, drawing on O'Neil (2012), he contends that from its inception, the values of 'equity' and 'efficiency' were in conflict. He maintains that while 'healthcare for all' is an appealing premise, health policy has also been guided by political and bureaucratic processes and interests, such that delivery is inevitably constrained. Armstrong finds that government, clinicians and patients commonly have different aims, agendas and priorities; in his view, the story of the NHS is about the 'working out of those contradictions' (c.f. Bosanquet 1997:7).[125] Beyond this, the originators of NHS did not anticipate the demographic transition the UK has undergone over the last 70 or so years— an ageing population with increasingly complex health needs has combined with increased reliance on ever-more advanced and costly medical procedures and advances

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[125] Pushkar's ethnography with NHS activists points to the embodiment of these contradictory forces; from activists' perspectives, the NHS is a 'social(ist) institution' that embodies 'equal right to healthcare for all', whereas from the perspective of service providers, it must take into account its financial and resource constraints in order to survive (2018; 241).

in scientific knowledge, these trends challenging the sustainability of provision as it was initially envisaged.

It was soon apparent that the 'need' for healthcare far exceeded initial projections and in time the NHS began to struggle to meet rising costs and demand. Thus, successive governments have introduced a mix of governance and financial reforms, the emphases being funding cuts, combined with efficiency and accountability drives, marketization and devolution. Certainly, the financial challenges involved in running a large and complex national organisation were huge. With general taxation, supplemented by National Insurance Contributions (and nowadays also by nominal patient charges) the main source of funding, the institution has always been susceptible to national economic trends. Economic growth was particularly strong in the 1960s and the period was marked by a proliferation of new treatments and increased availability of medications. But a series of national economic downturns from the 1970s onwards left the NHS with serious financial shortfalls.

Political ideology has played a part in this process. In 1997 the Labour Government significantly increased funding and introduced new organisational structures in the NHS, with subsequent Labour Governments sustaining this trend until the global financial crash of 2008. Conservative Governments, however, have questioned the validity of the socialist model of public healthcare and focused on reducing public sector debt. This has been one of the primary motivations behind efficiency initiatives, which for Conservatives include marketization and internal competition, many of these representing significant shifts in the institution's management and delivery structures. In particular, austerity measures introduced after the 2008 financial crisis resulted in major reductions in funding to both public health and social care, a pattern that prevailed until the 2020 Covid-19 pandemic. Yet, all the while, the demand for services—and the cost of delivering those services—continued to grow. The upshot is that while the NHS has largely weathered these financial challenges, today's NHS looks quite different from the institution it was in the late 1940s; whilst, at the same time, its 'performance' (as measured by key performance indicators) has declined (Charles et al. 2019).[126]

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[126] 'Performance indicators' are inputs, outputs and the failure or success to meet key 'targets' (Klein 2019). Prior to the Covid-19 pandemic, the UK spent less on healthcare per person than most other countries with major state provision, including France, Japan and Germany for example.

In recent decades, tropes around accountability and patients' rights have played an increasingly important part in NHS efficiency reforms. These tropes find expression in a multitude of acts, policies, codes of practice and regulations introduced over the decades, which together are intended to standardise and better regulate healthcare. In the context of the NHS, accountability is taken to be the duty to uphold 'quality standards' throughout clinical governance and conduct (DH 1997), with performance assured by regular monitoring and evaluation of clinical procedures and outcomes (Bovens et al. 2014). Accountability is addressed through measures and procedures around confidentiality, recruitment and selection, equal opportunities in employment, dignity at work, fraud and corruption, professional performance and capability, disciplinary procedures and the like. These measures help guide patients in their rights and clinicians in their responsibilities, including in complex situations of mental distress, such when a patient is deemed unable to make decisions (legally termed, to 'have capacity')[127] concerning their health and wellbeing. However, throughout its history the NHS has struggled to achieve an appropriate balance between 'upward' accountability to institutional executives, government officials and funders (and thereby, ultimately, to taxpayers) and 'downward' accountability to patients. Mental health policy tends often to lean more towards the former than the latter, and in doing so often leads to complaints from service-users, particularly mental-health activists (as I show in chapter 3).

The adoption of evidence-based medicine (EBM) as the 'default language' of healthcare was intended to ensure that interventions would be "cost effective and measurable", a key plank of accountability and efficiency drives (Biehl and Petryna 2013; 8). EBM is based on randomised control trials (RCTs) in intervention design and cost-effectiveness and impact evaluations. Armstrong maintains that the evidence-based philosophy authorises 'economical, easily comprehensible and uniform justifications for treatment decisions, by linking clinic rationales to data from trials. In doing so, it orients a clinician's attention towards simple, standardised and quantifiable categories' (2017; 88). For Turner et al., concerns about efficiency and accountability and the resort to EBM in mental healthcare reflect a 'moral panic' about risk and unpredictability, their argument being that 'healthcare needs to fulfil obligations that pertain to value for money, care quality, transparency and prudence; these obligations require quantitative documentation based on standardised metrics and scales so that good clinical care is by definition accountable' (Turner et al.,

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[127] See section 2.3, this chapter.

2015; 55). 'Good' healthcare is thus about mitigating 'risk' (arguably for the NHS rather than the patient), in that *"Data may determine policy, rather than human opinion, judgment or custom"*. Armstrong argues that in this way, decision makers potentially avoid responsibility and blame (Armstrong 2017; 71).

Governments have also attempted to improve NHS efficiency and accountability through devolution and the gradual introduction of an internal market system. While some see marketization as necessary for sustaining universal healthcare, it is a cause for concern among activists and has also attracted much controversy among service-providers and academics. Pollock persuasively argues that this development fundamentally changed the 'doctrine' and 'culture' of the NHS, with commercial values such as 'income security and profit' replacing the institution's service ethos (Pollock 2004, ix).[128] Certainly it has led to the mushrooming of private health providers that appear to be motivated as much, or more, by profit as they are by patient wellbeing. Related to this, some observers point to the proliferation of diagnostic categories, coupled with the exponential rise in both diagnoses[129] and treatment regimens (Dillon et al 2011; Cummins 2018) as sparking increased demand for pharmaceutical products and consequently benefitting the pharmaceutical industry above all other interests (c.f. Lakoff 2005). As just one example, prescriptions for anti-psychotic drugs rose exponentially in the 1990s (Bossewitch 2016; Brenman 2019).

Devolution of health delivery was part of an effort to change how health services were commissioned and planned and has proved one of the most consequential NHS reforms. It has increased responsiveness of services to local needs as well as regulation of service quality and outcomes, these being important contributors to efficiency and accountability. However, no matter what advantages devolution has entailed, there has been much criticism of the process. In particular, the move is seen as merely transferring the care 'burden'—including any shortcomings in care—from central government to regional authorities and communities, without giving them a commensurate say in health policy or resource allocation (Edgley et al. 2012). Others perceive devolution and marketization as an insidious process of state retrenchment from, and privatisation of, public health care (Walker 1997; Pollock 2004; Kearns and Joseph 2006).

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[128] Many historians of the NHS link changes in its functioning to different eras such as the 'managerial revolution' that took place from the 1980s onward (Klein 2019).

[129] For example, diagnoses of generalised anxiety disorder increased by 9% between 2007 and 2014 (Mental Health Foundation 2017).

The devolution process began with the 1990 NHS and Community Care Act, which transformed the internal structure of health institutions and local authorities, dividing their functions between them. Local authority departments were charged with assessing the needs of the population in their area and purchasing the necessary services from hospitals and other providers. The Act also created General Practitioner Fundholding and NHS Trusts, the latter designated as 'providers' in the internal market, thereby competing with each other. From 2001 to 2013, the bulk of the NHS budget was managed by Primary Care Trusts (PCTs). These were largely administrative bodies, responsible for commissioning primary, community and secondary health services from providers. Until 2011, they also offered community health services directly. The Care Quality Commission (CQC) was launched in 2009, this being another step to increase efficiency and accountability through the independent regulation of NHS services in physical and mental health, and social care. The CQC was charged with assessing the quality as well as safety of healthcare, through regular inspections and monitoring. Data rating hospitals' performance were made available publicly, another measure intended to increase transparency, efficiency and accountability.[130]

Devolution was accelerated between 2010 and 2016, with central government increasing local authority responsibility for health and social care budgets. Widespread reforms introduced through The Health and Social Care Act 2012 saw the abolition of PCTs and their work taken over by Clinical Commissioning Groups (CCGs). CCGs are autonomous, regionally organised bodies comprised of local GP practices and they take responsibility for the planning and commissioning of local services from qualified providers in their region (Leys 2016; 12). Secondary health care, including mental health, is commissioned by CCGs and provided by NHS Foundation Trusts. The way that CCGs work means that each region and each trust have a different way of supplementing and delivering services.[131] However, all CCGs are intended to be 'downwardly accountable'; to reflect local priorities and needs (Armstrong 2017; 64).[132]

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[130] The intention behind making hospital data available publicly was to increase competition between hospitals (so as to win market contracts) and thus increase efficiency. For a critique of the logics and discourse around transparency, see (Sanders and West 2003).

[131] For example, individual organisations–such as Hospital Trusts–can generate additional income through parking charges, land sales and treating private patients (Charles et al. 2019).

[132] All service providers—in clinics, hospitals, community centres, and so on—are accountable to their CCG.

While the NHS has, since its inception, been dedicated primarily to healthcare, a proportion of NHS patients have severe and/or long-term health problems that may involve additional costs and/or make it impossible for them to work—these conditions bringing health and social-welfare provision together. This is a circumstance that many, if not most, of my interlocutors contend with. In these cases, NHS health delivery involves close coordination with the DWP, which manages and distributes benefits, such as Personal Independence Payments (PIPs)[133] and Employment and Support Allowances (ESA).[134] PIPs are non-means-tested, non-contributory, tax-free payments intended to help adults meet the costs associated with long-term health conditions disabilities and are issued whether individuals are in or out of work. ESAs on the other hand, are for individuals who cannot work and are intended to be a substitute for their earnings. Entitlement to an ESA is based on medical assessment reviews conducted periodically by independent healthcare professionals[135] from the Health Assessment Advisory Service on behalf of the DWP. These assessments use criteria set out by government around mental, cognitive and intellectual function. They evaluate individuals' competencies in learning, awareness of everyday hazards, planning, organisation, and problem solving, prioritising tasks, coping with change, social engagement and appropriateness of behaviour towards others. Many activists find ESA assessments extremely stressful, as I show in chapter 4.

2.3 NHS mental healthcare

The legal and policy framework

Historically it was thought that the condition of people with long-term or serious mental-health diagnoses would never improve. Countless people with such diagnoses were therefore confined to designated institutions, where many were severely maltreated (Turner et. al 2015).[136] The 1890 Lunacy Act, which until 1959 provided the foundation for mental health law in England and Wales, placed an obligation on local authorities to

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[133] PIP helps towards some of the extra costs arising from long term ill-health or disability and is based on how a person's condition *affects* them, not the condition they have.
[134] The 1942 Beveridge Report created the framework for the modern welfare state and in 1945 Beveridge introduced welfare reforms covering the whole working age population. PIP was introduced in 2013 and was intended to replace Disability Living Allowance (DLA) for people aged 16-64. Now, many benefits are being rolled into one 'Universal Credit', with increasing focus on getting people back into work.
[135] Doctors, nurses and physiotherapists.
[136] 'Mad' people have been confined to asylums and madhouses since the amendment of the Poor Law in the 16th Century, which stipulated that local parishes were responsible for their care in institutions.

maintain asylums for those deemed to be mentally ill.[137] Improving the treatment and living conditions of people diagnosed with severe mental illness was one of the key concerns of the newly-emerged welfare state in the late 1940s (Pereira, 1997).[138] The Mental Health Act of 1959 was a major step in that direction. The Act set the terms for certification and compulsory detention, and together with the 1962 Hospital Plan, provided for the closure of asylums and assimilation of psychiatric care within the hospital system (Turner et al. 2015).

That said, a commitment to 'de-incarceration', in and of itself, was insufficient since such a policy also implied the need to increase funding and provision for community-based services, as well as to devolve responsibility for delivery to local authorities.[139] However, while successive governments recognised the necessity for institutional change, mental healthcare remained a relatively low priority throughout the 20th Century, as mentioned— and was also seriously disrupted by the wider NHS reorganisations (ibid). [140] The maintenance of community care was failing, due to inadequate services, the overburdening of families, an outdated legal framework and other factors, so a new national mental-health strategy for England was introduced in 1998. Entitled *Modernising Mental Health Services,* this strategy was part of a series of target-driven reforms of NHS provision, and detailed plans to both increase investment and escalate management over clinicians in general psychiatric services, increasing the standardisation of behaviour and responses to patients (Marshall 1999). Additional funding was provided for more beds for hostels and secure units, as well as more outreach teams and 24-hour access, among other measures. Increased control of patients was to '"ensure compliance with appropriate treatment" (in the community) and permit "a new form of reviewable detention for those people with a severe personality disorder" (ibid, 3). Control of clinicians' practices focused on standard settings via NICE and inspection through the Commission for Health Improvement.

Along with increased regulation of services, quite a few of the NHS reforms were directed at securing patients' rights. Nonetheless, mental-health patients do not necessarily perceive themselves as having the scope to assert their rights. This is particularly noticeable among individuals with more serious mental-health problems, for whom the

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[137] The 1930 Mental Health Treatment Act allowed mental hospitals to treat patients without certification.
[138] Turner et al. (2015) argue that this policy focus remained until 1997, though was marked by a preoccupation with 'dangerous' people as much as with the provision of resources.
[139] As in the 1990 National Health and Community Care Act.
[140] For example, even though spending on mental health was increased by Labour Governments between 1997 and 2010, the growth of general expenditure in the NHS was greater.

interplay between therapy and care on the one hand and containment and force on the other is ever present. Indeed, activists regard mental healthcare more as a form of violence and an abuse of power than a form of therapy and few feel they have a say in improving these circumstances. The Mental Health Act (1983) (amended in 2007) is one of the reforms that most affects activists. It was introduced to protect and strengthen the rights of citizens who are detained due to 'mental illness' and at risk of harming themselves or others. Although it covers many situations, it is most often employed in the treatment of people with 'severe' mental-health conditions, for example by specifying the circumstances under which individuals can be detained without their consent (often referred to as "sectioning"). Detained patients may be hospitalised or receive treatment at home under a 'Community Treatment Order' (CTO), their rights depending on which section of the Act they are held under.[141] The Act also stipulates that persons who do not behave as instructed by the police or social workers have a high risk of being sectioned.

Stipulations on the use of force and forced treatment in the Mental Health Act are of particular relevance to mental-health activism. For example, even though individuals deemed to 'have capacity' are allowed to refuse treatment, clinicians may use powers bestowed on them in the Act to overrule their wishes. Similarly, decisions about which setting is to be used for treatment are also made by clinicians. And even though the right to privacy is an important principle in the Act, confidential information can be shared without the patient's permission if the clinician considers that to do so is in their interests. The Act also requires service providers to have a written policy on, keep a record of, and commit to reducing, the use of force, and to inform patients about their rights in such situations. The Use of Force Code of Practice provides statutory guidance on the use of force in mental healthcare. Termed 'restrictive interventions', force is delineated as: 'deliberate acts on the part of other person(s) that restrict a patient's movement, liberty and/or freedom to act independently in order to:

> Take immediate control of a dangerous situation, end or reduce significantly where there is a real possibility of harm to the person or others, and when restrictive

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[141] The most commonly used sections are: Section 2: Admission (to hospital) for up to 28 days for assessment; Section 3: Admission for up to six months, in the first instance, for assessment and necessary treatment; Section 4: Admission in an emergency (only one doctor needs to agree to the detainment initially); Section 37: Hospital order by court; Section 37/41: Restriction order by court; and Section 136: Police power in public places to remove person to a place of safety (NA 2022). In 2015 the CQC stated that forcibly detained inpatients made up 51% of the total number of inpatients (CQC 2015).

interventions are required, they should; be used for no longer than necessary to prevent harm to the person or to others; be a proportionate response (DCA 2007).

The Code requires hospitals to train all staff who may need to administer a restrictive intervention.[142] In the case of death or serious injuries, the Act requires mental-health units to have regard to all relevant NHS and Care Quality Commission (CQC) guidance. Finally, The Mental Capacity Act (2005) (updated in 2007) is also highly relevant for activists. Originally, it laid out the circumstances under which decisions could be made on behalf of individuals deemed incapable of deciding for themselves. It was assumed those persons in a permanent vegetative state, with dementia, or learning disabilities and also those who experienced 'severe' mental illness automatically lack capacity. The 2007 amendment was designed to 'restore power' to vulnerable people by working from the assumption that they have capacity unless *proven* otherwise.[143]

Mental health services and treatment pathways

NHS mental health provision for adults is supplied through specialised Adult Mental Health (AMH) services operated by Trusts as part of the system of secondary health care. Delivery is undertaken by multidisciplinary teams comprised of mental health nurses, occupational therapists, psychologists, social workers, psychotherapists and psychiatrists—each of which has distinct skills and roles and provides specialist support to patients.[144] In addition to prescribing medication (the responsibility of psychiatrists) and referring patients for psychological talking therapies, teams can assist patients with finding accommodation, among other things. Mental-health clinicians are trained in one of three disciplines—psychology, psychotherapy, and psychiatry. The biomedical paradigm predominates throughout NHS clinical practice and shapes staff training, as well as patients' diagnoses, treatments and outcomes. Patients diagnosed with psychotic disorders are generally treated by psychiatrists, who make extensive use of psychotropic medications. [145] Mental-health services are generally accessed via referrals from a

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[142] It also states that patients should not be deliberately restrained in a way that impacts their airway, breathing or circulation. Staff should monitor their airway and physical health throughout the intervention (DCA 2007; 24-26).

[143] This act was an important victory for activist interlocutors and one they drew much hope from.

[144] The latter are medical doctors who specialise in mental health.

[145] See the (DSM-5 2013). The key priorities in NHS psychiatric care have been the use of psychotropic medications to shape mood, behaviour and cognition (Turner et al., 2015, 59). There are five main types of psychotropic medications: antidepressants, anti-anxiety medications, stimulants, antipsychotics, and mood stabilizers.

General Practitioner (GP) or another health professional. However, there are exceptions to this rule, as when individuals present to Emergency Services, or are sectioned and it is also possible to access some services through self-referral via NHS websites. An NHS statement explains the basis of current mental healthcare in the UK;

> … a wide range of interventions for adults aged 18–65 in a community or hospital setting. [..] The day-to-day framework for services is based on the Care Programme Approach (CPA) and the rules of the NHS and Community Care Act 1990 (CCA).[146] When a GP refers a patient and the AMH service accepts this referral, the stages of care are: assessment, planning, intervention and then discharge back to the care of the person's GP […] about 80 per cent of people who experience mental health distress are supported by their GP (SCIE 2012; 1-2).

Delivery strategies depend on the diagnosis and discipline of the clinicians, though all treatment pathways are subject to NICE guidelines, which prescribe specific interventions for specific clinical conditions. The guidelines are drawn up by independent committees, mainly using EBM based on RCTs that assess 'how well a medicine/ equipment/ procedure works in relation to how much it costs' (NICE 2010).[147] Having been endorsed as 'scientifically proven' and 'empirically supported', the guidelines are taken to represent the 'gold standard' (as in the best available) for mental healthcare in the UK (Bruun 2019; 42). As one example, NICE guidelines on treatment options for people with diagnoses of an acute exacerbation, or recurrence, of psychosis or schizophrenia include oral antipsychotic medication, administered often in conjunction with psychological and psychosocial interventions. These latter include Cognitive Behavioural Therapy (CBT) and family intervention (which may be started either during the acute phase of distress or later, including in inpatient settings). Although they have significant influence on NHS treatment, it is important to note that NICE guidelines are only recommendations and therefore are not always employed in practice. For example, they may be adapted to accommodate resource limitations. Also, based on evidence from qualitative research, national statistics (i.e., Singleton *et al.* 2003; NICE 2022), and the experience of my interlocutors, delivery

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[146] This Act introduced a broad requirement for local authorities to help vulnerable adults remain in the community, preventing or delaying admission to institutional care.
[147] The independent committees include professionals and lay members, and the guidelines are consulted on by stakeholders.

schedules often depart from the guidelines.[148] However, despite variations in delivery, the guidelines do represent 'TAU', in that they specify basic standards in and treatments for mental healthcare. In short, they signify current 'institutionalised responses' (Cummins 2019) to mental-health provision.

Some of the most common treatment pathways in NHS mental-health provision are relatively short-term and designed specifically for persons diagnosed with depression, anxiety or other neurotic conditions. In 2008 the government established the IAPT Programme to address shortfalls in NHS mental-health services.[149] The Programme was intended to increase access to talking therapies and enable adults experiencing anxiety disorders and depression to better manage their mental health.[150] Drawing on CBT, it comprises a range of psychological treatments, including face-to-face and digital therapies such as apps and online programmes, which are derived from EBM (Brenman 2019).[151] Sessions are time-specific and a patient's 'progress' is gauged through regular outcome-focused monitoring and supervision, these features being intended to increase treatment efficacy (NICE 2022). The original intention was to deliver the Programme at scale and in 2015, it treated 560,000 people. The 2019 NHS Long-Term Plan committed to further expanding mental-health services through the IAPT programme. The aim was to serve an additional 380,000 adults per year by 2023/24, mainly with psychological therapy accessed online via 'e-therapies' (Parkin and Powell 2020).

Despite the commitments to boost services, it is seldom possible to treat individuals who experience complex, long-term mental distress through a single, time-bound intervention; more often, they require an extended process that may involve multiple measures and providers. Those with a mental health problem that lasts longer than six months and needs the care of three or more health professionals are provided for via tailored Care Plan

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[148] Thus, although antipsychotic medications are often offered to patients when they first present at mental-health services, many wait a long time before they are able to access psychological interventions. Moreover, while many interlocutors have experienced treatments such as CBT, very few have accessed family therapy, and among those who have, it was years ago, when 'things seemed less stretched'. These patterns are confirmed by other studies (Petryna et al. 2006; Rapley et al. 2011).

[149] IAPT providers are required to meet the annual targets for recovery rates instituted by the CCG that commissions the services. Providers that fail to meet recovery targets risk having their funding cut. In some cases, the CCG might decide to close the service altogether and allocate resources to other NHS services (HSCIC 2017).

[150] Talking therapies are psychological therapies that involve talking to a trained therapist about thoughts, feelings and behaviour (NHS 2019).

[151] CBT combines principles from behavioural and cognitive psychology and is used to treat anxiety and depression, among other psychopathologies. CBT focuses on challenging and changing behaviours, (e.g. thoughts, beliefs, and attitudes) improving emotional regulation, and the development of personal coping strategies that target solving current problems (NHS 2019).

Approach (CPA) (NHS 2019). CPAs are mostly used for those deemed to have a 'wide range of needs' or to be at 'high risk' in terms of their mental health (Rethink 2013)—this includes several of my interlocutors (see chapter 3). CPAs were introduced as part of a shift in mental healthcare from a fundamentally paternalistic approach towards one that puts patients 'at the centre of decision making about local services' (DH 2000). The idea was that improving coordination in mental healthcare and delivering services in partnership with patients would better provide for patients' needs. CPAs are supposed to outline an individual's key goals in relation to treatment and recovery, document the type and frequency of support needed (including medical care and equipment), and specify how much will be spent on that person. They also include strategies for handling emergencies, as when an individual is sectioned, or held to lack capacity. A CPA is when both "patient and professional act *in partnership* [my emphasis] to identify goals and select the combination of treatments and services most likely to achieve them" (Mitchell; 2013; 136). NHS guidelines on care plan partnerships are as follows,

> Personalised care and support planning is a systematic way of ensuring that individuals living with one or more long-term condition and their health and care professionals have more *productive and equal conversations*, focused on *what matters most to that individual*. It is a *collaborative process between equals,* whereby people with health and care needs, along with their family and/or carer, work together with care practitioners (NHS 2016; 11).

> The approach of 'personalised' care and support planning as a *collaborative and person-centred* process is … <u>NOT</u> about any of the things below: developing a traditional treatment plan for individual services; a process intended purely to aid health and care practitioners in making decisions about an individual's care and treatment... It is NOT solely about traditional medical solutions; a one-off 5-minute conversation; *something which can be prepared by the care practitioner and the patient agrees to; a tick box exercise which results in a standardised plan that can be copied and used for any individual with a particular condition or similar circumstances* (NHS 2016; 16-17—my emphasis).

The partnership rhetoric aligns closely with trends in the NHS towards patient 'empowerment', 'autonomy' and 'patient-centeredness', processes that some see as radically transforming mental-health provision (Malby 2012). The empowerment paradigm can be seen in the Recovery Model, which conceptualises service-users as active agents

in achieving better health as opposed to passive 'recipients' of care. The assumptions are that the more patients have a sense of 'ownership' of, and help shape, their treatment, the more likely it is that they will trust the process, thereby increasing the probability of recovery. A King's Fund document entitled *Patients as Partners* lays this thinking out when it says that the intention underlying therapeutic partnerships is to "disrupt the 'them and us' relationship in health and care systems" (Seale 2016; 4). According to this perspective, patients bring valuable insight and expertise to their treatment, their contributing complementing the clinician's knowledge. This view is reflected in an NHS guide on co-production in the design and delivery of public services, which defines the process as "the meeting of two experts" (Realpe and Wallace; 2010, 11). The development is part of a broad teleological shift in mental healthcare, as Pomey et al. (2015; 1224) make clear; 'quality healthcare decisions are based on two complementary forms of knowledge: the scientific knowledge of health professionals and the patient's own experiential knowledge'. Coulter and Ellins highlight the benefits, with the clinician bringing "knowledge of diagnosis, treatment options and preferences, aetiology and prognosis and the client knows about the experience of illness, social circumstances, and attitudes to risks, values and personal preferences" (12; 2006). Thus, the idea that different types of knowledge and expertise work together to inform a greater understanding in the clinical setting is well established.

Although co-production has gained considerable currency in NHS mental healthcare in recent years, there are many pathways into and through treatment and the tension between compulsion and patient-led approaches is ever present. This is especially true of psychiatric interventions, such as the enforced hospitalisation and treatment of patients diagnosed with particularly serious psychotic conditions. Electro-Convulsive Therapy (ECT), in which electromagnetic currents are sent through the brain under an anaesthetic as a 'stimulus' to alleviate acute symptoms, is one of the more controversial examples for activists. Although its use has decreased significantly in recent years, ECT continues to be administered to people with 'severe mental illness', when all other avenues have failed, or a person's life is thought to be threatened. It is also administered to people who are 'treatment resistant', meaning individuals who refuse, or do not respond to, medication. Some of the most engaged interlocutors in the three activist networks I researched had undergone ECT, while others have been threatened with it during acute crises.[152] From

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[152] One respondent recalled when he was being restrained multiple times a nurse 'joking' with him, told him that if he didn't stop 'acting up', then they would have to give him ECT.

the perspective of patients and many clinicians it remains one of the most contested forms of treatment for mental health. Campaigners argue for its abolition not just because it tends to be administered under force, but also because its effects are unpredictable and occasionally harmful.[153] As such, it is held by some to violate patients' fundamental human rights.

Debates and controversies in mental healthcare

In spite of a growing acceptance of the importance of mental health in political circles and efforts to improve service efficiency and impact, there remain many critics of mental healthcare in the UK. Even though the NHS is somewhat de-centralised, and the services delivered through regional Hospital Trusts and GP practices are extremely diverse, much of this criticism applies to generic forces that shape, or are perceived to shape, the NHS across the board. It is also important to note that many of the concerns raised by service-users are shared by service-providers and researchers in anthropology and health.

For some, the efficacy of NHS provision has been continually undermined by government interventions that they see as giving greater priority to fiscal considerations than to mental health. The austerity programme introduced after the 2008 global financial crisis put significant financial pressure on the NHS and resulted in major cuts to welfare payments and social services, all of which negatively impacted service-users, including individuals who had been reliant on welfare benefits. For example, the Department of Work and Pensions (DWP) reduced Incapacity Benefits (now, ESA) for those unable to work due to mental distress (between 2006-2007) (Rizq 2012; 8). Greco and Stenner (2013) link 'austerity politics' (the reduction of government budget deficits by reducing funding for services) directly with the objectives and design of specific mental-health initiatives, arguing for example that the IAPT Programme was intended primarily to lighten the financial load of mental healthcare. Turner et al. (2015) concur, highlighting how the Programme was planned to generate economic returns nationally by reducing overall levels of mental ill-health,

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[153] Patients who have undergone ECT report memory loss, 'brain fog', confusion, drowsiness, numbed emotional responses and difficulties with cognitive processing as among the main 'side-effects' (as indicated by NICE 2013).

> Lord Layard's IAPT programme was built upon evidence that untreated anxiety and depression placed a large burden on primary care services and that patients preferred non-pharmacological therapies but laid a new emphasis on the economic case that high levels of mild to moderate mental illness in the population were a drag on prosperity (*ibid*; 609).

Brenman finds similar logics at play in her ethnography of a London-based mental-health service,

> Crucially, the logic of IAPT was less about ideologies of what precise therapy was being delivered or whom it was for, so long as it could be shown to "work." It did not matter what the therapy looked like, as long as the data on recovery said that the clinical need was disappearing. Need, in other words, was there to be met. (Brenman 2019; 154).

Even though it may have positively impacted service delivery in important ways, the push towards greater accountability and efficiency in the NHS after 2008 is a particular cause for concern among activists and researchers in mental health. Accountability and efficiency measures have left many feeling that managerial and bureaucratic procedures take precedence over patient wellbeing. For example, the emphasis on EBM in healthcare is seen as prioritising market-driven factors, such as quantification, targets, cost-cutting, cost-effectiveness, contracts and resource saving, over and above all others (c.f. Rizq 2012; Moth 2013). For Harrison, EBM and marketization promote the kind of measurable, 'knowable' knowledge found in clinical trials, this being based on 'an underlying logic that treats medicine and healthcare generally as capable of explicit specification, rather than esoteric, indeterminate or dependent on tacit knowledge' (2015: 73-74). IAPT services are a constant area of debate and controversy among activists and the focus of numerous campaigns and meetings. For many, one of the most serious impacts of accountability and efficiency initiatives is that they drive "the therapeutic increasingly toward measurability" in mental health (Matza 2018; 148), in turn, undermining clinical relationships. Armstrong argues that though bureaucratic accountability may have facilitated uniformity in care standards, it has also served to disempower patients and chip away at clinician's contributions (2016; 51). Similarly, Hautamäki observes;

The tick-the-box diagnostic questionnaires were used to assess and measure patients' individually experienced moods, thoughts, feelings and behaviour. These tools served to stabilise the uncertainty in the clinical encounter, but diagnostic tools can transform psychiatric practice into a technical performance undermining the importance of the clinicians' experience and knowledge (Hautamäki 2018; 59).

Certainly, e-therapies and other standardised treatments help service providers trace clinical decisions and ensure they are 'accountable' according to agreed criteria. This enables them to meet standardised targets, thereby minimising 'risk' and helping to reduce medical 'uncertainty' and, as Armstrong and others argue, decreasing their anxiety. Thus, clinical decisions are no longer based on personal intuition or knowledge, lessening the level of personal responsibility in clinical practice; if clinicians follow the guidelines and do what they are supposed to do, then they are protected by law. However, for many, the waning of clinical intuition and tacit knowledge is to the detriment of patient care. For example, Armstrong reasons that it has given rise to a generic pattern of interaction between therapists and patients, which he terms 'routinised intimacy' (2016; 236). Routinised intimacy renders service providers unable to respond effectively to individuals, especially those presenting with (what service providers term) 'complex' problems. Standardised approaches to patient care removes spontaneity and subjective valuation from treatment and shuts out complexity, doubt and uncertainty. Further, even though patients are meant to be at the centre of interventions, diagnoses and treatment options are generally decided on by service-providers with little or no consultation with users. Similarly, there is little attention to the experiences and perspectives of patients (MQ 2015).

In their discussion of the history of mental healthcare in the UK, Turner et al. (2015) maintains that the recent financial struggles in the NHS have played out through 'moral imperatives' that lead professional and organisational priorities away from patients and towards accountability. Similarly, Pushkar (2018) maintains that health professionals attune themselves to accountability procedures, time-keeping processes and quotas on the understanding that to do so is essential to the very survival of the NHS.[154] In other words, they internalise certain ideas about how the NHS 'should work' and behave in ways that 'allow' the institution to persist whilst also enduring the constant strain on its

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[154] Bruun found similar concerns and negotiations among UK therapists; they discussed IAPT as 'the only way' of developing public mental health in the face of economic scarcity, reminding one other to 'be realistic' and 'think in business terms' (Bruun 2019, 190).

resources. Pushkar calls this the 'naturalisation and normalisation of austerity', involving a tacit acceptance of the change in the NHS ethos of healthcare from one based in socialist values to one prioritising managerial efficiency (ibid; 241). Armstrong similarly observes how 'economic forces operating at an international scale might be felt as moral imperatives in the clinic' (2017; 77). Thus, 'clinicians feel obliged to be impartial, to reason in a particular kind of way, to produce particular kinds of justifications for their care' (Armstrong 2017; 82) in a way that makes their therapeutic work 'accountable'.[155] He goes on to say that the "values of auditing become internalised by staff members to the extent that external rules and internal dispositions merge" (2017; 59). In this sense, patients' needs are displaced at the hands of NHS procedures and narratives that was once structured around rights to health and liberty but have now become dominated by organising categories such as 'cost', 'risk', 'needs' and 'values' (Turner et al. 2015). In order to fulfil their roles as accountable professionals, healthcare professionals must manage clinical interactions in ways that "might appear to be the antithesis of open, trusting, intimate relationships" (Armstrong 2017; 206). Armstrong's ethnography demonstrates that internalising the institutional rhetoric of 'making do' gives rise to conflict for professionals; they may not agree with how this rhetoric shapes their practice, or feel comfortable applying these norms, yet compliance is understood to be both a statutory and a moral 'duty'.

Drawing on O'Neil (2012), Armstrong, argues that such shifts in the culture of clinical practice have seen the NHS move from a "trusted machine to [an] accountable service provider" (2017; 28). According to O'Neil, loss of trust in the NHS reflects a wider crisis of trust in institutions across the UK. He writes;

> Amid widespread and energetic efforts to respect persons and their autonomy and to improve regulatory structures, public trust in medicine, science and biotechnology has seemingly faltered […] particularly in the UK, there is evidence

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[155] Lester (2018) writes about a similar dilemma among therapists in a clinic for eating disorders in the US. Healthcare systems privilege use of biometric data in diagnosis and treatment, leaving clinicians feeling that their relationships with patients are simultaneously both "critically important and structurally devalued, and their affective investments in clients to be both vitally necessary and personally and professionally risky" (ibid; 523) partly because of the constraints and pressures of insurance companies. They find themselves responding to demands that they be both emotionally available and remain emotionally protected from patients simultaneously.

that mistrust of various professions, experts and public authorities is quite widespread (O'Neil 2012; 3)

Walshe and Shortell also highlight the connection between accountability procedures and service-user mistrust, arguing that while the focus on accountability gives "the impression that information is open and transparent" (2004; 642) there is evidence of NHS staff concealing information in order to protect the institution instead of its patients (ibid; 107). Similarly, a recent report declared that there was "an institutional culture [in the NHS] which ascribed more weight to positive information about the service than to information capable of implying cause for concern" (Pope 2015, 94). In other words, rather than acknowledge the inherent "indeterminacy of health" (Grecco 2004; 459) professionals make efforts to 'perform certainty' (Montgomery 2013) for their clients.

The power dynamics in healing relationships also play a vital part in issues of trust. Armstrong holds that, "because [patients] know less, they must trust others from a position of epistemic inferiority" (2016; 23). Similarly, Grimen argues that 'differentials in knowledge and opportunities of control are what it means to be a professional' (ibid; 16).[156] He goes on to suggest that the use by professionals of 'discretion and clinical judgment are difficult to make accountable' (Grimen 2001; 19). Activists echo many of the concerns raised in these accounts; many individuals do not perceive the NHS to be a particularly 'trustworthy' institution. I show in chapter 3 that activists' wariness of mental healthcare runs deep and manifests in multiple ways, especially through suspicion and fear about the corrosive nature of clinical relationships. Several activists report concerns about the conduct of professionals, for example acts of sexual violence and harassment committed against patients.[157] Other studies of the NHS document similar problems, including claims around clinical incompetence and negligence, as well as the many adverse effects of treatment.[158]

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[156] Grimen maintains that because clinicians are 'socialised to see themselves as beneficial helpers' they do not perceive themselves to be 'gatekeepers and controllers' (2009; 16).

[157] As an infrequent visitor to FLL once exclaimed; "It's quite sinister really that public services cannot be held responsible. The NHS and social services are held in high esteem by the British people, but what would they think if they got into conflict with them like we have?"

[158] It is not just public or patient trust in the NHS which has been raised as a concern; Pope's study demonstrates that NHS staff feel like there is a 'culture of secrecy and suspicion' which leads to lack of trust (2015; 96).

For activists, one of the main controversies around clinical practice in NHS mental healthcare concerns the use of compulsion. They point to what they experience as the arbitrary and unjust use of sectioning and other forms of enforced treatment. Related to this are questions about whether patients who are seriously ill have a valid perspective on their treatment and how long they can or should be detained (sectioned) against their will. I recount interlocutors' experiences of enforced sectioning and restrain throughout this thesis. Many recalled these episodes as moments when, as far as they are concerned, logic and rules go out of the window and described feeling lost, with their opinions and rights ignored. Emergency changes made to the Mental Health Act at the outset of the Covid-19 pandemic in 2020[159] added to their apprehension. The most significant change was that whereas previously assessments around sectioning had to be undertaken by two clinicians, now only one psychiatrist is required. Interlocutors used to find the involvement of two psychiatrists reassuring as they saw it as likely to result in a more balanced judgement. They fear that awarding such a significant decision to a single clinician increases the likelihood of the diagnosis reflecting personal agendas.

One other trend that concerns activists and researchers in the context of marketization and accountability is the growing individualisation of mental-health interventions. My research indicates that, in practice, the person-centred approach manifests less as respect for patients' perspectives and more as a struggle between different ideas about mental health. I show that there is continuous tension in clinical encounters between clinicians' efforts to pose certain predetermined questions around patients' needs, along with the requirement that this information be obtained within a limited time period, and interlocutors' wishes that treatment address very different, more fundamental, questions. Further, the focus of therapy is on individual feelings, behaviour and functioning (Forster and Gabe, 2008), which highlights how clinicians regard as mental health as being shaped by cognitive, affective and emotional—as opposed to political-economic and social—processes. This can be seen, for example, in popular treatments, such as CBT. With these treatments giving weight to 'negative thought patterns, extreme thinking and unhelpful behaviour' (Boyes 2008; 24), clinicians encourage patients to look inward on themselves and on their personal behaviour and responses, rather than on social-structural forces or circumstances. However, as far as activists are concerned, this approach amounts to a denial of their reality, or lived experience, a circumstance that aggravates rather than

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[159] This was partly introduced in response to a shortage of trained and qualified mental health staff during the pandemic.

lessens their mental distress. Skultans's ethnography documents a similar process, finding that "where sadness might once have been associated with dissent towards the Soviet authorities, it is now a personal failing and generates a burdensome sense of guilt, that, ironically, seems to make the distress worse" (2007: 262). Some critics (particularly those influenced by Foucauldian understandings around self-governance—e.g., Edgley (2012); Rose (1998) atttribute this kind of framing to the 'neoliberalisation' of mental healthcare, in which persons are aware of, participate in and reflexive of, their own governmentality (Lemke 2001).

The emphasis on 'self-led management' and personal responsibility in mental-health and social welfare provision raises additional concerns (Forster and Gabe, 2008). As with similar tropes, self-led management is held to be more about reducing the financial burden on the state than facilitating the mental health of service-users (Mind 2008). The stated purpose of intervention is often to enable individuals to function independently and return to work following illness, the underlying assumption being that people who experience mental illness lead less fulfilling lives and enjoy fewer opportunities than healthy individuals. For example, 'back to work' schemes, DWP 'fit for work' notes and other such measures have been credited with directly decreasing the need for persons to rely on formal services (NIMHE 2005; 3). Service-users (Stickley and Wright, 2011) and the critical health service and anthropological literatures (Edgley et al. 2012; Whitley 2015; Carpenter-Song 2015) levy similar criticisms at the 'Recovery Model', which was introduced recently as part of reforms intended to make mental-health services more responsive to patients' perspectives and needs. The model, "seeks to engage service-users in a process of self-defined, goal-orientated healing" (Edgley 2012; 122) in which recovery is defined as 'a return to a state of wellness', or the 'achievement of a personally acceptable quality of life' (ibid; 2012). However, critics argue that the requirements for and indicators of 'recovery' employed by service providers are often at odds with the views of service-users. Indeed, there is evidence that the model can have a deleterious effect on mental health.[160] For example, Estroff's (1985) ethnography of a psychiatric ward shows that schemes designed to increase productivity and self-esteem may serve instead to undermine patients' competency, agency and sense of selfhood because few are able to realise their aspirations to obtain 'a real job', or even undertake 'adapted work' (1985:

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[160] 'Work is not a health outcome' was an ongoing campaign for one of the activist groups.

145). Such concerns about NHS mental healthcare have led a sizeable minority of service-users to take up mental-health activism, as I indicate in the next section.

2.4 Mental health activism, patient discontent and resistance in the UK

In this section, I provide a brief history of mental-health activism in London, focusing on the ideas and aims that resonate most closely with those expressed by my interlocutors. The three activist networks that I worked with—Friends of London's Loons (FLL), the Resist Mental Health Network (RMH) and Stand Against Psychiatry (SAP)—have unique characteristics and identities. However, there are clear parallels with other groups involved in the broader UK mental-health activist movement—and for that matter activism more generally. They maintain commitments to and affiliations with past activist groups such as Mad Pride through their documentation and public talks about their history.[161]

'Mental-health activism' is an umbrella term used by activists to denote individuals who are critical of mental healthcare—or 'TAU'—and engage in activities that express their discontent and desire for change. The history of mental health activism in the UK is complex and encompasses many different viewpoints and objectives as well as a range of organisational types and structures.[162] Thus, Callard observes that the 'criss-cross' landscape of mental health politics constitutes an 'assemblage of relations, partnerships and critiques' (2014; 4), while Crossley (2006) talks in terms of 'fields of contention'. In his ethnography of mental-health activism, Bierski (2014; 14) identified a 'huge amount of activity between loosely networked groups across the UK as mental health activism', though noted that there was a recognised need for 'organised and mutually supportive collaboration'. Thus, for example, it would not be appropriate to characterise mental-health activism in London as being against psychiatry; the aims are far broader and more multifaceted. Activists report diverse and conflicted relations with psychiatry, psychology and other disciplines, self-identifying varyingly as 'psychiatric survivors', 'mental health

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[161] See the Survivor's History group (Survivor History Group; n.d.)

[162] Anti-psychiatry for example has a long and multifaceted history. For key figures, precedents and advocates of the movement, see (Foucault 1954; 1961, Porter 2002, Laing 1960; 1967; 1996, Szasz 1974; 1975). For a comprehensive sociological history and review of anti-psychiatric activist movements in the UK see Crossley (1998; 1999; 2001; 2002; 2004; 2005; 2006; 2007)

service-users and survivors', 'service evaders' and 'ex-service-users' (for more on this see chapter 1). There is a recognition among activists that they do not have to have, and likely will never have, a unified coherent voice, though some encourage collaboration and support between networks.

Turning to the motives behind mental-health activism, the underfunding of and institutional challenges in the NHS over recent years has been a major factor. Many activists express deep concern about austerity policies, workfare and what they perceive as the 'medicalisation of misery', due to the expansion of psychiatry and increasing reliance on pharmaceuticals (Moncrief et al. 2014).[163] There are additional worries about changes in the way mental healthcare is delivered (for example, the digitalisation of therapies, such as e-therapy) and many activists are angered by discourses around individual responsibility for mental health and the demand for mental healthcare being described as an 'epidemic'. But the one concern shared by most activists, is the reliance of mental-health provision in the UK on the biomedical model of medicine. This model is understood by activists as being intrinsically tied up with the professional, bureaucratic, and political establishments that regulate both mental illness and the lives of the mentally ill—regulation being seen as a vehicle of constraint and control rather than a mechanism for improving mental-health outcomes (Moncrief et al. 2014; 44). Critiques of the model also centre on the way attributes mental health to personal factors, particularly the biology of the brain and the nervous system. Activists place far greater emphasis on lifestyles and social and economic conditions underpinning mental distress, this involving a fundamental aetiological shift (Altman et al. 2012). For example, poor mental health is perceived to be associated with the dominance of market-driven values and the way they corrode relationships (Pratt-Boyden 2012). Allied with this viewpoint, conventional therapeutic relationships in the context of biomedical practice are regarded as transactional and therefore as inherently tainted.

Beyond the critiques of biomedicine, psychiatry has always maintained a central position in mental health activism. Members of FLL, SAP and RMH, would not identify as being 'anti-psychiatry', although they draw clear parallels between theirs and the anti-psychiatry movement. The anti-psychiatry movement arose in Britain during the 1960s, along with a Europe-wide effort to bring an end to the institutionalisation of people with poor mental

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[163] As Jupp notes, anti-austerity politics have been "springing from communities and from the everyday lives of citizens experiencing cuts" (2019; non-paginated).

health (Fakhoury and Priebe 2007). Some of the key anti-psychiatry campaigns revolve around specific treatments administered to people diagnosed with schizophrenia, including medication given without consent (sometimes called 'forced drugging'), psycho- or neurosurgery, ECT and sectioning. As well as its treatments and methods, the ethos of psychiatry is critiqued. Since the 1990s, one particular group, 'Mad Pride', has become increasingly influential—this marking a significant break with orthodox criticisms of psychiatry. Bossewitch (2018; 5) argues that Mad Pride advances a "more nuanced critique of mainstream perspectives on mental illness than earlier generations of anti-psychiatry activists", its rhetoric being less about rejecting systems of psychotherapeutic knowledge and more about celebrating the diversity of human experience. However, a general aversion to clinical/ professional authority and the medical establishment is still very prevalent in such groups. This is implied, for example, in their advocacy around self-determination and self-sufficiency in the management of mental distress (Bossewitch 2017, 3) and their concern for the subjective experience of wellbeing over objective indicators. In activists' view, people who suffer mental distress (or 'madness') have unique insights into the causes, consequences and experiences of such conditions. The 'mad' person is thereby positioned as the 'expert' of their own experience,[164] which is very different from TAU, in which all the expertise is thought to reside with the clinician.

There are other therapeutic communities and self (or mutual) help groups that also resist the marketization of health care, psychopharmacological treatments, and the clinical relationships underpinning biomedicine (Adame & Knudson 2008; Crossley 1999). For example, the Soteria house project is a residential community that aims to deconstruct conventional therapeutic relationships, and place residents at the centre of their own care.[165] Likewise, peers in the Hearing Voices Network aim to de-medicalise group sessions, focusing on the phenomenological, lived experience of voice hearing, and rejecting prescriptive pathological explanations of their state of mind (Noorani 2011, Blackman 2001; 2007). Noorani has written how, as a result of challenging the hegemony of medical paradigms and accepting "the validity of personal journeys of recovery, as imbued with meaning and significance" (2011; 11) indeterminacy has become accepted as a norm within these groups.

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[164] Noorani helpfully notes that "the authority of the expert-by-experience is granted because the advice of the e-b-e is relevant to everyone" (2018; 228).
[165] Similarly, the Basaglia therapeutic community in Italy tried to reject materialistic, individualised approaches by 'turning to the body' and practicing self-liberation in a communal setting (c.f. Scheper-Hughes and Lovell 1986; 1987).

RMH, SAP, and FLL have a number of foci in common; including the structural disparities associated with capitalist society and developing holistic modes of healing that empower those experiencing mental distress. Rejecting both their own diagnoses and biomedical treatments more generally, some activists seek the abolition of psychiatry specifically, whereas others strive for the closure of all mental-health services. Others still are less radical and rather than eradication, struggle for broad, systemic reform of mental healthcare and social welfare. For example, some networks simply hope for greater self-determination for NHS patients—including more autonomy and control and a greater say in their interactions with services, aims articulated through use of phrases such as 'being heard', 'being seen' and 'proving I am here'.

RMH is an important player in mental-health activism in London and engages in both direct action and consciousness-raising. A London-based network established by people who suffer from mental distress across the UK, it maintains that the lack of mental healthcare, together with the unreasonable conditions imposed by the welfare state, exacerbate mental suffering. RMH members defend affected groups 'from the assault…by a cruel government whose only constituents are the superrich and who value everyone else according to how much they serve the interests of this selfish minority' (2016; anon). They are particularly troubled about the linking of health and work support, including the relationship between work coaches and mental-health professionals. They do not regard criteria such as capacity, functioning and the ability to hold down a job as appropriate indicators of good health and, pointing to the pressures to get people with mental-health diagnoses into work, perceive mental-health services as serving government (post)austerity targets rather than the wellbeing of people in receipt of benefits. Thus, their recent campaigns have focused on challenging the assumption that resuming work is a positive mental-health outcome for individuals and resisting the pressures on those diagnosed as mentally ill to return to work. In their direct actions and consciousness-raising work these groups subvert and expose their vulnerabilities as a radical tactic of their resistance. Further to this, they also honour and celebrate their vulnerability, which not only resists austerity but also demonstrates alternative interdependent possibilities.

Activists in the SAP network are more focused on psychiatry specifically, perceiving it to be an abusive practice. They reject the psychiatric definition of mental distress as being caused by brain disorders and chemical imbalances, and express significant disquiet

about coercive treatments such as Electroconvulsive Therapy (ECT) and sectioning. Concerned about the relationship between pharmaceutical companies and psychiatry, they also decry the over-prescription of medications that are often addictive, and from which withdrawal can be difficult. They advocate for a more holistic understanding of mental health that takes full account of the individual's historical and social context. They employ a range of campaign strategies to raise awareness of the harms of psychiatry, and to imagine a future in which psychiatry is held accountable. To achieve their aims, they focus on public education, lobbying government bodies, building cases for legal action and undertaking other formal complaints procedures. FLL is a 'ginger' group [166] that operates from the same perspective as Survivors of Services. Open to service-users, carers and professionals, it aims to raise greater awareness of what they term the "Psychiatry Cosh" and oppose the use of drugs.[167] They also campaign for fairer and more compassionate approaches to the care of psychiatric patients, seeking to empower them to find more effective approaches to managing their mental-health.

Having summarised some of the most important endeavours of activist groups in London, I turn now to the motives expressed by individual interlocutors. I asked my interlocutors why they had joined mental-health networks and why they participated in specific campaigns. However, despite a strong sense of antagonism toward biomedicine, mental healthcare and the welfare state, their motives were often quite unclear. In fact, very few expressed a political affiliation and it seemed that for many, activism is more about giving meaning to their lives. For example, Clare, a shy, often indignant woman who trained as a nurse, responded that engaging with other 'survivors' enables her to "live some sort of life". Julie, a creative and persuasive woman who lives with her teenage son, described how activism gives her a sense of purpose, allowing her to support others. Lissa, an artsy, Scottish woman in her sixties with a big personality- one of the few who lives in her own home with her cat- explained that being on benefits helps because not working or participating in 'the rat race' leaves her with the time and energy to reflect on things that are 'bigger' than she is and to engage in collective action on behalf of those who do work. She sees this kind of altruism as giving her a sense of purpose and meaning.[168] Referring

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[166] 'Ginger group' is a political term for activists acting as democratic 'sister groups' of a movement, so FLL is a 'sister' of the mental health activist movement. Ginger groups lobby as catalysts for change by identifying alternative, radical ideas, intended to be of benefit to the wider movement.
[167] 'Chemical cosh' is a phrase denoting drugs which are used to subdue persons. Psychiatry cosh is an adaption of this phrase.
[168] Lissa's comment in particular is interesting in light of Desjarlais's (1997) ethnography of residents in a Boston homeless shelter, in which 'struggling along' implied the "daily strenuous efforts against an

more specifically to peer support, Mike noted that although his role can be burdensome, 'the point of peer support is that you get something back. It is actually quite uplifting, because you see people who are struggling and finding ways to live life and look up, instead of despairing. That keeps you going.' He did not specify what that 'something' that he gets back is but always explained peer support as a reciprocal process, in the sense that what he gave, he also received in kind. This could plausibly include satisfaction or pleasure in the act of helping others, feelings of worthiness, closer relationships, or learning how to manage his own suffering through exposure to the experiences of others. Some activists practise activism through both collective action and individual acts. Andy, for example, is determined to see systems reform. To that end, he seizes every opportunity he can to critique and even defy service providers, as well as taking NHS authorities and politicians to task. As I show in chapter 3, he was willing to put his care plan in jeopardy by challenging his psychiatrist's expertise in mental health and its treatment. When I explained how impressed I was by his efforts, he replied, "I'm not brave, it's not a decision, or a choice…" But to highlight Andy's acts of resistance is not to suggest that activism by individuals operating on their own is typical. I found most interlocutors to be far less assertive than Andy in their interactions with mental-health and social-welfare staff. In fact, with so much riding on the outcome, I found many activists to be fearful and submissive in their exchanges with service providers. Thus, for many interlocutors, political engagement involves collective action channelled through and run by mental-health networks.

2.5 Chapter conclusion

In this chapter I summarised key developments in the history of the NHS since its foundation. I suggested that its priorities have changed over time and that its original socialist values focused on universal free healthcare have been compromised by the necessity of sustaining a large, complex system under huge financial pressure. I made this case by detailing how the NHS has become increasingly shaped by accountability, efficiency and market processes. I continued by describing some of the main policy trends shaping NHS mental-health provision specifically. I highlighted how the institutional culture

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often-hostile world, with little opportunity for inward reflection or for planning the future" (Desjarlais 1997).

is articulated through 'Treatment as Usual', wherein the pressures to be accountable and efficient manifests powerfully in clinical practice. The 'routinised intimacy' enacted by professionals, together with their anxiety to comply with auditing procedures, can undermine trust and transparency in clinical relationships and also produce conflicting values for them. Thus, despite professionals' efforts, relationships that are meant to be built on collaboration and partnership—in which clinicians' scientific, evidence-based, knowledge and the subjective knowledge of patients are both meant to play a vital role— are regarded by interlocutors as an abuse of power. Understanding how activists experience mental healthcare lends important insights into their grievances around the biomedical model and related aspects of provision, which I explore throughout this thesis (particularly in the following chapter) and conceptualise as the 'absent presence' of treatments.

In chapter 3, I explore routinised intimacy and accountability through activists' interactions in clinical settings by introducing two of my interlocutors, Andy and Nadia. Drawing on data from one of Andy's care-coordination meetings and an ESA assessment involving Nadia, I discuss the connections between NHS mental-health treatments and social welfare provision, highlighting the difficulties such connections present for activists. In the remaining chapters (chapters 4 to 6) I focus on the 'afterlife' of NHS mental healthcare, showing how interlocutors reinvent themselves and their social worlds in opposition to their encounters with the system.

Chapter 3: 'Magic and Mental Gymnastics': Activists' Experiences of Mental Healthcare and the Welfare State

As if by magic or mental gymnastics, words like 'support' and 'help' take on a different meaning when it's medical practice.

Will (2018)

3.1 Chapter introduction

In chapter 2, I summarised the historical context and approach underpinning mental healthcare in the UK, focusing in particular on the NHS. Among other issues, I highlighted the link between NHS mental-health services and DWP social-welfare provision. In this chapter I explore interlocutors' experiences of these two systems. With monitoring a central plank of NHS and DWP accountability procedures, interlocutors' access to benefits is mediated by eligibility assessments focused on mental health. I argue that in many cases these assessments set the tone for interlocutors' interactions with the wider mental healthcare and benefits systems. I do so by drawing on data from one such encounter—involving Nadia. I also touch on interlocutors' wider engagement with mental-health and social-welfare services. I show that interlocutors express considerable antipathy towards these services, their criticisms ranging from infractions by staff to the intransigence of bureaucratic procedures. Since sectioning and restraint of patients with complex chronic mental-health conditions is commonplace (chiefly in psychiatric hospitals), the greatest concern is the normalisation of physical violence, emotional and sexual abuse.[169] Many describe these experiences as having long lasting adverse affective and health impacts.[170] However, regardless of activists' immediate concerns, they have an underlying disquiet, which centres on the supremacy professionals award the biomedical model in mental-health.[171] This concern is exemplified by an exchange between Andy and his care-

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[169] Violence in this context is the suffering caused by "deliberative and systematic medical acts and processes" (Mary 2019; non-paginated).

[170] As explained in chapter 1, I decided against interviewing mental-health staff for this thesis. Thus, this chapter draws entirely on my own observations, information available in policy and other documents and reflections shared with me by activists. It does not therefore reflect the perspectives of service providers.

[171] Following the convention employed by many interlocutors, I use 'biomedicine' as an emic term that encompasses all NHS mental-health treatments as though they are a single, homogenous entity, when in practice, as noted in the introduction, they embody many different approaches and practices.

coordination team. According to biomedical framing, both pathology and therapy pivot around the individual.[172] Interlocutors, on the other hand, regard mental distress to be a social construction with societal conditions its primary cause. I demonstrate that activists' concern is not just with differing conceptions (or what Kleinman terms 'explanatory models' 1978) of mental distress, but also the way these conceptions lead to divergent understandings about what is important to describe or represent. For example, the title of this chapter is taken from a quote by Will, who expressed disbelief that clinicians' conceptions of help and support could differ so fundamentally from his own. Activists argue that clinicians cannot see beyond their paradigms and training, to the extent that they inhabit a different version of reality. More than just a different paradigm, they regard clinicians' understandings of and approach to, healing 'illness' as an ontological denial, partly to keep social order and hierarchies in place (also conceptualised as an epistemic or hermeneutical injustice, see introduction and chapter 2). This, in turn, leads to the re-telling or indeed silencing of their truths.

The chapter is divided into five sections. In the first, I summarise activists' experiences of mental-health treatments of various kinds. With so many activists in treatment and/or depending on a diagnosis for accessing welfare benefits, biomedicine affects practically all aspects of their lives. I therefore introduce the metaphor of a 'shadow' in this section to emphasise the pervasive presence and quality of biomedicine in interlocutors' lives.[173] In section two I examine the interactions between Andy and his care-coordination team during a care-plan assessment. I highlight the discord between the two sets of actors, maintaining that this discord is due to the disparity in their conceptions of mental distress. Using Nadia's ESA assessment as an example, I explore the impact on interlocutors of the interlinking of NHS and DWP accountability procedures in section three. I show that while NHS policy emphasises the importance of collaboration and 'partnership' between service providers and service-users (NHS 2016), eligibility assessments are perceived by interlocutors as gratuitously bureaucratic and intrusive. In section four I argue that poor communication combined with lack of information in both appraisals and treatment increase interlocutors' sense of anxiety and mistrust—some responding through sarcasm, humour and other intentional acts of resistance. The chapter concludes by discussing the

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[172] The 'psy-iences' is a term used by social scientists to refer to "'the disciplines and professions concerned with the human mind, brain and behaviour' including but not limited to psychiatry, psychology, psychotherapy, social work, psychosocial approaches, psychoanalysis" (Raikhel & Bemme 2016; 151).
[173] My conceptualisation of the shadow of biomedicine reflects work by Delaplace (2012) and Street (2018) on the manifestation of spirits in particular societies, and Varley & Varma (2018) Janina (2018) and Avery (2008) on the hauntings of places such as hospitals.

concept of 'magic and mental gymnastics' – a phrase Will used to describe the discordance between patients' and professionals' constructions of mental health care. While interlocutors may need, and indeed seek, both benefits and therapeutic support, doing so often incurs high levels of stress. This is not just because the bureaucratic obstacles are many, but also because they do not trust what is on offer. I end by suggesting that interlocutors' experiences of mental health and social welfare provisions are a major motivation behind their political activism as well as their efforts to forge alternative/therapeutic worlds.

3.2 The shadow of biomedicine

Even though successive governments have tried to apply uniform regulations and standards across NHS mental-health provision, treatment trajectories do not necessarily follow a common pattern. Thus, activists' experiences of mental healthcare have varied and continue to vary significantly. Multiple factors shape treatment pathways, including how patients encounter service providers, where they live (which part of town, area, or region), their medical history, and the degree of support they receive from friends, family and others. Moreover, time scales vary enormously. While treatment can be seriously delayed, changes in treatment can be so rapid that patients struggle to adjust. Also, while medical guidelines are meant to provide a degree of predictability around treatments, patients may not be aware of these guidelines or understand them, a situation that leaves many feeling anxious. Below, I summarise the trajectories of three interlocutors, to give a sense of the diversity of diagnoses and treatments pathways available.[174] That said, I should highlight that these simple sketches outline linear journeys through treatment, which is something of an illusion because most of my interlocutors experience these pathways as quite chaotic.

Greg, a charismatic, honest, and boisterous man from North Yorkshire, had never used mental health services before. He had been feeling 'lethargic' since losing a job, which occurred around the same time as a bad argument with his mother, of whom he is very fond. He presented to his GP in West London and explaining that he was having trouble sleeping and concentrating, asked to be signed off his current job. He was diagnosed with

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[174] The information was obtained through interviews.

'moderate' depression (which he was not informed of but discovered much later from his medical notes). The GP prescribed antidepressants to help with the immediate effects and put Greg on a waiting list for talk therapy.[175] Greg reacted badly to the antidepressants and ended up at Accident and Emergency Services (A & E) after becoming more despondent and ceasing eating. In A & E he received a second clinical diagnosis, 'severe' depression, and was advised to stay on the antidepressants until his mood stabilised. As Greg was not able to work, he applied for disability benefit, but missed his first appointment with the DWP. The GP then increased his dosage of antidepressants.

Like Greg, Austin had not used mental-health services before. A very thoughtful, quiet man, at aged 22, he experienced a lot of stress at work and was having trouble fitting in at university. He went to A & E after experiencing hallucinations, which he found 'terrifying', whilst out with some friends. He underwent an emergency assessment with a liaison Psychiatrist (after a 4-hour wait at A & E) and was diagnosed with a paranoid psychosis. He was given a prescription for antipsychotics and returned home under a scheduled 'early intervention' crisis treatment programme. This involved a member of the community mental health team visiting him at home every few days.[176] The community mental health nurse missed his first appointment, though Austin was not informed why.

Will has been in and out of services (including hospital) for over a decade. He has a dual diagnosis of schizophrenia and autism, which he was given in his early twenties. On one occasion he was found talking to himself and was arrested by the police under section 136.[177] The police took Will to see a psychiatrist. Will was assessed and then detained under section 3.[178] Will refused to take antipsychotics orally and was given a depot injection by force and hospitalised for 6 months. Will then applied for and underwent a mental-health tribunal, the outcome of which was not what he had hoped for. His section 3 was renewed. Will spent another 6 months in hospital, then was released under a second tribunal and placed in a housing scheme, on condition that he regularly receive

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[175] The average wait is 8 months.

[176] Early Intervention Services (EIS) work with people specifically following their 'first episode' of psychosis. In some areas of England, EIS stop once you are over age 35. The service involves psychiatrists, psychologists, community psychiatric nurses, social workers and support workers.

[177] This section allows police to take a person to a place of 'safety' (i.e., a hospital or police station) without a warrant under the premise that they are in need of 'immediate care and control' (Mental Health Act 1983).

[178] Under section 3, a team of health professionals assess the person's mental health and decide that the best way to provide the care and treatment needed is to admit them to hospital. They can stay there for up to 6 months.

depot injections. Will is required to visit a mental health outpatient centre daily (ordered under a CTO in compliance with the Mental Health Act, to be renewed every 6 months). He has regular CPA meetings with a psychiatrist and care-coordinator and has free access to housing and disability benefits under Section 117 (ongoing).

Some interlocutors are undergoing intensive long-term NHS treatment, while others dip in and out of therapy and others still reject all services, though continue to access benefits through a prior mental-health diagnosis. Being diagnosed with psychosis or other long-term conditions can leave people stuck in treatment for a long time, or experiencing forced treatment, with little sense of control or cure. Andy has been diagnosed with schizoaffective disorder and, as I noted in the prologue, sometimes jokingly refers to himself as a 'revolving door patient'. This phrase is used often by health professionals and activists, although with markedly different meanings. For activists, it is the experience of being "passed around from one professional and one treatment regime to another because no one knows what to do with you, with the effect that the treatment is repeated endlessly without benefit".[179] By contrast, for clinicians a revolving door patient is someone who is 'uncooperative' and/or 'complicated' in healthcare terms (Williamson et al. 2014). The phrase 'revolving door syndrome' also appears in the medical literature, where it refers to patients who are deemed unsuitable for long-term care but are readmitted regularly to psychiatric units (Garrido and Saraiva 20120) and removed from GP lists due to their "unreasonable expectations, inappropriate behaviours and unmet needs" (Williamson et al. 2014). Shaw is critical of this framing since it serves to construct patients as 'difficult' and renders any treatment shortcomings as their problem, when, in practice, transferrin patients from one service to another reflects more fundamental systemic difficulties;

> The dynamics of exclusion lie in the break-down of the "normal" doctor-patient relationship coupled with the doctor's need to get on with the day's workload. Moral judgments from professionals and others form a part of the exclusion process of the patient (Shaw 2004; 1032).

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[179] Andy explained many times that he would not need to use services if he had more support from friends and family. He is estranged from his family in Scotland, and because he is constantly in and out of hospital finds it hard to make friends.

Apart from the sense of being relentlessly pushed from pillar to post, many interlocutors have had deeply painful and disturbing experiences of treatment. Will cited an incident involving mental health nurses in the hospital he was detained in under section. He had refused to ingest an anti-psychotic pill, so one of the nurses held his arms down and another threw the pill into his mouth in such a way that he was forced to swallow it. Although the nurses insisted that they were acting in his best interests, he was hurt, and felt humiliated and powerless. He said that the incident felt as he imagined he would feel had he been raped. Will interpreted their actions as follows:

> It's incredibly obvious when you're taking a drug that they actually give you, that this is not something to help you – it's to help other people. This is something to shut you down, make you more docile – it makes it hard – they're not even caring about how you think, it's about how you behave. And when they talk about making it manageable – or making your 'condition' manageable, it does literally mean your behaviour. Your 'condition' is literally your behaviour to a psychiatrist or a psychologist.

Some interlocutors find themselves continuously (re)experiencing and revisiting these historical ordeals, which seem to follow them like a shadow. An argument between Clare and Eric (both regulars at SAP) that erupted at a SAP meeting is illustrative of the way these experiences 'haunt' interlocutors. Clare had posted something Eric had said at the previous meeting on Facebook. Eric, a retired schoolteacher, pointed angrily at the minutes of that meeting, which showed that SAP members had agreed that these discussions would be confidential, and not relayed on social media. Clare retorted that she had agreed to "no such thing". Eric replied, shouting, that it was imperative she not break his trust and guarantee his privacy in meetings. Clare responded by launching into an account of how, once, when she was sectioned, she had been forcibly restrained by hospital staff, who in doing so, broke her arm. She went on, her voice breaking, "they brought on an abortion, but they didn't care." She explained that the hospital was not aware that she was pregnant, and the staff had pushed her roughly to the ground. By this time, she was furious—her eyes wide open and face tense, she was shouting and staring into space as though in another world. There was a stunned silence. Then Leo, a gentle, soft-voiced man in his forties, intervened by conveying his sorrow to Clare at her loss. However, Leo seemed confused, thinking that the hospital staff had coerced Clare into having a chemically induced abortion. In a voice full of solemnity and rage, he began

describing instances where patients had been administered drugs in their food without being given a chance to consent. By this time Clare was too worked up to correct him and the group moved on to discuss forced medication.

This episode was striking in that Clare's experience was so painful that she brought it up spontaneously during an entirely unrelated conversation. The reasons for Clare's interjection are unclear, but it is possible that the argument with Eric had 'triggered' the memory of a moment when she was rendered extremely vulnerable and felt under attack. Then again, she may have sought to deflect attention away from her breach by rapidly shifting the group's attention to a subject that she knew would attract their sympathy. Leo's intervention moved the discussion away from Clare, his reference to forced drugging reminding all present of the helplessness and outrage they feel at what they understand to be a form of abuse. His comment also reflected the convention among activists to connect intensely personal experiences with wider social concerns (an issue touched on in section 3.4 of this chapter). Importantly, the rapid spiralling of emotions demonstrates how biomedical practice is experienced by activists as demeaning, harsh or unwarranted; these experiences often lingering in interlocutors' minds, leaving them struggling with a mix of difficult emotions. Another example of the powerlessness interlocutors feel when in treatment, is provided by Will. He recounted a troubling incident that occurred one night while he was in hospital;

> …There was basically another time when…there'd be like an incident at night. There was a guy, I think it was someone new to the country, an asylum seeker, was it Ghana? I'm not sure, I think he said, he spoke another language, maybe French more than English, his English wasn't spectacular. He was kind of friendly but scared and 'paranoid'. Paranoid was the word they used to warn me about him, they kept telling me he was 'paranoid'. But actually, I think, he was in a completely different country for the first time, and he had no clue what was going on. I don't know how he got there, but I could hear him calling the staff 'bullies', lots of crashing and shouting, I didn't know what was going on, but he was shouting something like 'they're breaking my bones' or something. All night it went on. And the next morning, you see some fucking blood on the floor, and that guy's gone. I don't know what happened to him, probably just moved to another ward or something, but you know, stuff like that goes on. Its chaos, people just come and go at random, and you never know when something's gonna happen. And when it does happen, it's

almost always between the staff and patients, the violence. Very little violence between patients. Cos it's quite a stressful environment, people are snappy and grouchy with each other, but I've seen more solidarity than aggression between patients. Anti-psychiatry views are immensely prevalent on secure wards, as you can imagine. Some of it's like – kind of wrapped up in conspiracy theory, some of it's more politics, because people come from backgrounds where it's like, you know, they have no idea what to make of it.

While hospital staff were constrained in what they could tell Will about the incident that night due to patient confidentiality, it is hardly surprising that Will was upset at being kept in the dark. It is common among interlocutors to worry about 'cover-ups'. Will speculated that the man had probably been beaten and hidden in a seclusion cell. The incident reminded him that, while in hospital, he too had no control over his fate, a sensation that caused him much anxiety. For example, he described his unease when a psychiatrist took him into a room one day, sat him down and said, "We're going to have to administer you with ECT". He was greatly relieved—though also somewhat dismayed—when the psychiatrist then looked up and, laughing, retorted, "Only joking, I'm kidding". Such concerns about having no say in, or being informed about, their treatment were common among interlocutors. These concerns included not knowing when they would be released from hospital, what kind of information is held in their medical notes, along with not being able to access, or even read or understand, these notes—particularly when they are in shorthand or medical terminology is used. Indeed, the failure to share medical notes with patients is hotly contested in activist circles, where it is characterised as speaking '*about* you *without* you'.[180]

Interlocutors had numerous other complaints about mental healthcare. For instance, experiences that mental-health professionals might identify as a delusion, hallucination or psychotic episode, are for activists merely a part of everyday reality. As far as activists are concerned, reality does not have to be consensual, nor should certain realities be relegated to the realm of pathology. They are also concerned that diagnosis of mental illness undermines their credibility in the eyes of clinicians. Time and again activists expressed anger and upset that these diagnoses result in their not being taken seriously, or even stigmatised, by the mental healthcare system. An example of this was when Janet broke

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[180] A slogan commonly used in mental health activism and disability campaigns.

her leg while in hospital. She described how, when she complained about the pain, the nurses claimed that she was exaggerating. She went on to explain that it was two full days before they agreed to examine her and when they finally did, it was established that she did, after all, need treatment. Disquiet about being ignored, misunderstood and/or misrepresented is especially prevalent among those who have been sectioned or receive benefits. In their view, this is tantamount to a refutation or misrecognition of their personal experiences, as well as what they know to be true.

A related grievance is that complaints of malpractice--whether around service quality or infractions perpetrated by staff—are regularly dismissed without investigation. Mentioned most often were sexual violations, whether committed directly against interlocutors themselves, or as described to them by friends or fellow patients. Allegations of sexual misconduct and other crimes often circulate around the FLL, SAP and RMH networks. The sense of outrage invoked by these incidents is intensified by the fact that interlocutors' efforts to obtain justice are seldom successful. For example, Amir, a father of two in his seventies, complained that when he reported to a Trust that he had been sexually harassed by one of their staff, he was removed from their service and told never to contact them again. Referring to cases in which rape had been covered up, Lindsey , an energetic woman involved in animal rights campaigns and with strong connections in the police, and Aki, a quiet man in his twenties who lives with his mother, cited "repeated and unresolved injustices" against activists to members of the SAP googlegroup; "Most people just don't realise the impact" wrote Lindsey, "they prevent you from living a semblance of the good life". Lindsey was not just upset about how her experience affected her, but the impact of these injustices on the wider group. For activists, such incidents raise wider concerns about mental healthcare. Reflecting on the Trust's response to his complaint, Amir said, "This is why we should never trust health professionals". Andy painstakingly documents news reports about psychiatrists who have been convicted of gross misconduct. Citing a case of a psychiatrist who was convicted for having sex with his clients, he explained that, "If it ever happens to me...I will already have all this evidence".[181] One of interlocutors' main worries is the difficulty of obtaining corroborating evidence when reporting malpractice. Steve, a nervous but assertive activist in his thirties, explained that he felt his complaints about staff were covered up, or somehow 'lost' in the system; "This kind of thing has happened in the past several times when I made complaints about the local

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[181] Just some of the examples Andy collected can be found in (Guardian 2022; BBC 2003; 2004)

psychiatric unit… my nephew's and niece's psychiatric records also disappeared and couldn't be found anywhere. It was too much of a coincidence really." These examples demonstrate how engagement with NHS and DWP services leaves interlocutors with a pervasive sense of anxiety and injustice.

Places of Therapy

The invasive memories associated with detrimental experiences of biomedical practice are apparent in interlocutors' relationship with the multiple spaces they inhabit. Generally, in the UK, patients diagnosed as mentally ill are treated in designated clinical places, whether a GP practice, psychiatric hospital, therapy room, or supported accommodation. These settings are designed (primarily) to facilitate the treatment process, whilst also ensuring that staff are safe and remain in control.[182] As well as being risk-assessed for privacy, surveillance and emergency back-up, clinical spaces typically convey a sense of professionalism through high levels of order, tidiness and hygiene and an absence of homely features.[183] Moreover, the same space is normally used throughout a patient's treatment, presumably to give them a sense of continuity and stability.

Whatever the intentions behind their design, interlocutors seldom regard clinical spaces as restorative. Rather, interlocutors commonly report feeling trapped in hostile clinical settings where they are subjected to harsh and/or unfair treatment. Thus, these settings are seen as reflecting the wider system of containment and control, which in their view is entirely antithetical to healing. Described variously as 'noisy', 'hostile', 'intrusive', 'cramped', and even, 'hell', or 'a place of nightmares', interlocutors regard psychiatric hospitals as particularly unwelcoming and unsafe. For example, Andy was placed in a hospital that was surrounded by beautiful grounds. Trying to put patients at their ease, the staff make much of the pleasant environment; for instance, when Andy arrived, a porter suggested he look outside at the beautiful view. However, their efforts did not change Andy's sense of being stuck in-place and, in fact, he felt as though her were being mocked;

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[182] There is a large and significant body of literature which argues that the institutionalisation of the mentally ill is a form of confinement and control see for example (Goffman 1961; Foucault 1965) and more recently (Sine 2008; Coldefy and Curtis 2010).

[183] Although, sometimes, carefully chosen objects, such as a picture or plant, are placed in clinical settings with the intention of making patients feel at home.

From the outside it did look kind of like a hotel, it did have nice grounds. On arrival… I caught a glimpse of a distant beach at certain angles. But as soon as I walk in reception area, they just basically take me through to security doors, down some steps; I was in the basement. There was very little natural light. It was a low-secure Psychiatric Intensive Care [PICU] ward… my room was like a cell. A big cell. It had a little window way up high with not much natural light getting in, depending on what time of day it was- it was very gloomy. The other side, they moved me to, it was on a hill, a bit more of a nice view, but who gives a shit about the view. I mean, would you go to a prison if it had a nice view?

Several interlocutors recalled feeling trapped in hospital. One described trying to find somewhere where he could sit without being observed by security cameras or staff. Others took up smoking in order to be allowed to take short breaks outside regularly throughout the day. Austin lamented that, "the important thing that you couldn't do in hospital is, just be alone and independent, and in a non-supervised way, discuss experiences with other patients and come to an understanding that you're not alone." Thus, being under constant surveillance adds to interlocutors' feelings of distress, conveying the sense that they not only lack privacy, but are also neither trusted nor properly supported.

Some interlocutors find the shadow cast by their hospitalisation so pervasive that they remain reluctant to enter anywhere that reminds them of that time.[184] On one occasion, Mike insisted on accompanying to an emergency appointment I had arranged with my GP. He sat patiently with me in the waiting room. However, when my appointment had finished and I returned to the room, he had gone. He texted me, explaining that he was outside (in the freezing November cold). He clarified that he had *tried* to stay in the waiting room, but the smells, colours and sounds reminded him too much of being sectioned, having been forced to spend years in hospital. He described how, as a patient, his movements were restricted, and there was nowhere to relax, or 'be himself'. He went on to reason that prior to his incarceration, he had been quiet and reserved, but the constant onslaught of sensory experiences in hospital, the throng of people and the emotions this invoked, had

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[184] During the Covid-19 pandemic, many activists expressed on social media how they are used to being "locked down" or "locked in", likening it to incarceration, as well as the limitations of distress - emphasising the isolation and alienation and drawing parallels with the mandatory lockdowns endured by the general public.

"beaten the shyness" out of him. His distress at the absence of 'homely' objects,[185] not being allowed to 'linger', or just 'be' in hospital, was evident. He explained that there was,

> …no privacy or space. Warden checks every 15 minutes, especially when you first arrive- when they do not know or trust you. You are told off for lingering in a corner or a stairwell. Sometimes I wanted just to stand and clear my thoughts, but I was told to 'move on'. You're not allowed to sit in certain spaces… men and women aren't allowed to sit together ... I got told off for just *talking* to a girl once. And you have to always keep your bedroom door open, even at night. You're barged in on in the shower, and staff refuse to leave until you tell them that you're fine.
>
> I became pretty anti-psychiatry in hospital. […] actually, a lot of my views of institutions were formed when I had nothing else to do but think about them. Because I was in a low stimulation environment…we wouldn't have a toilet seat in case you would use it somehow to harm yourself. Or you wouldn't have coat hangers in your wardrobe or doors on it, it would just be an empty wardrobe you couldn't put anything in.

In this example, Mike makes clear that the hospital environment lacked the everyday objects which make a place comfortable or even 'homely'. Somehow, *everything* about the hospital was a reminder that he was there against his will. Mike makes an explicit link between the challenges of being an in-patient in a psychiatric hospital and his rejection of psychiatry as whole. Common among interlocutors, this antipathy towards psychiatry has much to do with divergent conceptions of mental distress and ways of addressing it among clinicians and activists, issues I examine in greater depth in the next section.

3.3 "My reality is mine, and they cannot take that away from me"

In this section I draw attention to the dissonance between the mental-health framework deployed by clinicians and activists' experience and understanding of mental distress. I make the case that this dissonance is a major area of contestation for activists and one of the main reasons why they are antagonistic towards NHS mental-health provision. I

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[185] Anthropologists of material culture have highlighted the importance of objects for building a sense of personhood and identity. Bourdieu (1984, 1993), for example considers how objects in the home reflect wider aspirations and social status and Miller (2001; 2008) examines how domestic objects both echo and create identity.

illustrate this argument by describing a care co-ordination appointment that formed part of Andy's regular assessments. The dialogue between Andy and his assessors exemplifies how clinicians seek to track and address individual functioning, while activists place far greater emphasis on societal factors and regard mental distress as just one aspect of the complex and changeable fabric of their lives. In this case, the divergence of views was not just about conceptions of illness, but wider notions of wellbeing and care, with the two parties also employing very different temporalities in relation to these concepts. The exchange also shows how some activists resist the rhetoric and practice of biomedicine, in that appointments, questions, tick-box exercises and interview guides are at times antagonised, picked at, and negotiated by interlocutors.

Having been sectioned, Andy is required to attend biannual post-detainment appraisals at which his care plan is reviewed and if necessary, revised. This particular review was conducted at a London mental-health clinic by a psychiatrist, a mental-health nurse (the care coordinator) and a support worker.[186] Andy's relationship with mental-health services is complex. He has been on benefits and in and out of hospital for most of his adult life and therefore depends on psychiatrists not just for his treatment, but also housing and other benefits. Yet he is profoundly critical of psychiatry and psychiatrists and would like the field to be abolished altogether. The appraisal began with the psychiatrist posing Andy a series of questions from a list saved on his computer. Below are two brief extracts from this exchange,

> Psychiatrist: How are things at the moment Andy?
> Andy: Well, obviously I want to get my care package sorted out.
> Psychiatrist: How are you feeling, Andy?
> Andy: In what sense, doctor? Feelings and mood are different from one another. As you can see from my finger, I am no longer wearing a wedding ring. I want a divorce. My son is in [Country] with my wife, but I need to get my care package sorted out desperately as he might return any week now. His mother will stay there. It's a complicated situation so I'd like to see a family therapist also. I have taken on more caring responsibilities recently.

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[186] The basic concepts and function of 'care coordination' are outlined in chapter 2, which also briefly notes how interactions are expected to operate in this context (i.e., determined by 'partnership' and 'collaboration' between the patient and co-ordination team).

The psychiatrist continued:

> Psychiatrist: How are you sleeping?
>
> Andy: OK, but my bed is always unmade; I don't know how to wash the sheets. It's why I need a better care package, the taxpayers pay for my care package, but it's not good enough, so you are wasting their money. I bet if taxpayers knew the kind of quality of support I am getting, they would be up in arms…. If the right support package is put into place- and I appreciate this is a learning curve for all of us in finding a new way of giving dignity, respect, and allowing members of the neurodiversity community to establish themselves in British society, after …being subject to an institutional environment—then I am confident that over time, my character defect of not knowing how to take good care of myself will be addressed.

These excerpts underline the marked contrast between the clinical framework and Andy's personal experience. From the perspective of the care-coordination team, a diagnosis of mental illness typically rests on the presentation of a mix of behavioural, cognitive and/or affective symptoms.[187] The team was therefore charged with gauging the 'scale' of Andy's illness through questions centred on indicators of basic needs and functioning, such as diet, sleep and mood. Moreover, the assessment had a specific bureaucratic purpose—to review and, if necessary, revise Andy's care plan. Therefore, the focus was on instrumental matters that manifest in the present, rather than the wider existential issues that concern Andy. The entire exchange made clear that Andy's conceptualisation of mental distress is very different from that of the clinicians. Like other activists, Andy understands mental distress to be socially constituted—caused mainly by problems external to the individual. Hence his frequent attempts to link the personal with the political and to attribute his suffering to society's wider ills. The societal causes he cited are more persistent, generalised and intangible than those employed in the biomedical model, making his distress hard to classify, measure and treat. In fact, according to Andy's conceptualisation, most of the remedies for mental distress fall outside the remit of psychiatry.

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[187] For example, Lock and Nguyen show how clinicians are generally concerned to ease bodily pain rather than intervene in patients' daily lives (2010; 74), arguing that this approach stems from a particular western notion of the self as "bounded by the body… individualized and ahistorical." (Ibid; 301)

Some of the contestation in Andy's appraisal was around conceptions of 'care' and 'support'. While NHS policy emphasises that service delivery should be based on 'collaboration' and 'partnership', this is not how Andy has experienced care; nor is it what he seeks from the service. He criticised care staff for their lack of empathy and for showing little interest in him, asserting that, 'you need people who care - who take an interest in you as a person'. This also came up when he explained why he had stopped answering the door to community mental health nurses;

> They made attempts to give me cues [to clean my flat], but then they would look at their phones and be texting or taking calls; that doesn't give the right signals. They failed totally to take interest in me… They kept repeating irrelevant questions, such as 'are you religious?' The repetition of the same question…demonstrates they have no interest. I don't see why it's relevant whether I'm religious or not. The *simple truth* is, as the client, I do not want to talk about what the support workers bring into a conversation, and the support workers do not want to talk about the topics that I bring into the conversation.[188]

Andy told the psychiatrist to 'stop sending round nurses who have thick accents', arguing that they 'can't understand' each other.[189] As an observer, these particular comments were difficult to listen to because of their racist connotations. However, Andy's point was clear; he wants to be cared for by people he can communicate with on all levels. From Andy's point of view, the questions about religion represented a lack of understanding of, or interest in, his personal beliefs. He also pushed back on the idea of mutuality between service provider and service-user, seemingly arguing for his right to unconditional care and support;

> Nurse: You do need to have a care package. I need your support …
> Andy: No, *I* need *your* support…

Andy's comments pointed to a mismatch between expectation, hope and reality,

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[188] Maintenance and daily hygiene have been well documented as markers and indicators of health professionals of health or illness, and the issue comes up often reflected in medical notes. The point was concerning for activists, as they often felt their personal hygiene was judged and pathologized. See (Tarlo 2016) for example for a discussion of hair as a sign of madness if not properly maintained.
[189] Andy is aware that others find him difficult to understand since he has a strong Scottish accent and a speech impediment.

Andy: The problem is, I want the skills to clean, but the workers you send me – we fail to communicate.

Psychiatrist: The difficulty is, Andy, your expectations are quite high…

Andy: The NHS is a world-class service. I don't think my expectations are too high… I accept that I have a responsibility for my actions, but also, I have been a victim, and the two things do co-exist, and it is important for me to own both these elements of my experience before I can become, what is called 'a functioning member of society'.

There was clear sarcasm in Andy's point about becoming a 'functioning member of society', as there was in his reference to the NHS being a 'world-class' institution. Andy's comment highlights both his disappointment in the NHS and the potentially unrealistic consequences of its ambition to provide good quality care at a low cost. Further, 'restoring' individuals to society and enabling them to live independently are important clinical objectives in the NHS (see for example WHO or NICE guidelines etc. (NHS England 2017; WHO 2019). But, given that he views treatment as designed to do anything other than to restore individuals to society, Andy thinks that these objectives are hypocritical. For Andy, a functioning member of society is not simply about living independently but being recognised as a legitimate and contributing member of society with attendant rights to care and assistance. Though he takes some responsibility for his care, he seemed to be arguing that he lacks the necessary skills to become autonomous and needs greater and more appropriate support to achieve this end.

Rather than discussing his care plan, Andy appeared to be seeking to engage in an exchange that is more typical of therapy. However, the team were unable to comply with these terms, so the plan was not completed; the only decision made was to 'carry on' with the treatment programme, as before. Realising that they were running out of time, the team offered Andy another appointment, but he refused, reasoning that an additional meeting would be futile given they disagreed on so many fundamental issues. However, in spite of his combative attitude during the appraisal, after it was over Andy seemed worried. He commented, "That meeting went terribly, the psychiatrist refused to acknowledge anything I was saying. I am not actually part of my care plan." Initially I was surprised by this comment because the psychiatrist had consistently responded to Andy's questions. But on reflection I realised that he had indeed refused to engage directly with some of Andy's questions, deflecting the conversation away from topics Andy had raised

and answering others superficially and without sincerity. The assessment did not yield positive results. Andy continued to be visited by the same nurses and the same disagreements arose between them. Having failed to maintain his flat properly, he was threatened with eviction. Eventually, he went missing. Andy's care-coordination assessment was revealing not just because it emphasised the dissonance between clinical explanatory frameworks and activists' approach, but also because it highlighted how dispiriting it can be for service-users to be subjected to what they perceive to be indifferent bureaucratic procedures. I examine this topic further in the next section, which explores the long-term impact standardised assessment protocols have on interlocutors' distress.

3.4 "They are watching you": the tyranny of the brown envelope

I now discuss interlocutors' experiences of and perspectives on the intertwining of NHS and DWP accountability procedures. I focus particularly on a Work Capability Assessment; this procedure being intended to establish whether an individual's illness or disability affects their capacity to work. Such assessments are a vital component in the benefits system, since they determine a person's eligibility for an Employment and Support Allowance (ESA). Conducted by the Health Assessment Advisory Service on behalf of the DWP, they rely on a series of tests, most of which involve completing standardised protocols.[190] I argue that ESA assessments create barriers between service providers and service-users. Possibly more seriously, because they can result in applicants being refused financial support and sanctioned, they are regarded by interlocutors as particularly intrusive and distressing. With so much at stake, interlocutors go to extraordinary lengths to prepare for ESA assessments. In order to be considered eligible for support, patients must present and communicate their distress in particular ways, most of which, I maintain, belie their lived experience and obscure their true concerns (c.f. Armstrong 2016; Armstrong & Pratt-Boyden, 2021).[191] Further, the merging of healthcare and welfare assistance means that interlocutors are defined as both 'patients' and 'benefits receivers',

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[190] Clinicians often use screening tools to assess a patient's condition. These include care-coordination assessment forms, IAPT surveys, and wellbeing scales. See for example the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) a very popular method used to determine wellbeing.

[191] This finding resonates with other studies, which suggest that the bureaucratic demands of the welfare and health systems risk intensifying rather than remedying mental distress (i.e., Pilgrim 2007; Bond et al. 2019).

positions that mark them as dependent and needy from a social perspective. This dependency renders them vulnerable to the vagaries of a system they perceive to be callous and unjust. Seeing themselves as actors with a right to shape their treatment and care, interlocutors are thus caught between two distinct subjectivities—both deferring to and relying on a system they regard as doing more harm than good, while simultaneously seeking to assert their agency by fighting for their rights as service-users and for wider systems reform.

As a first step, ESA applicants are required to send a completed Capability for Work questionnaire to the Health Assessment Advisory Service. The outcome of their application and next steps are communicated through a letter, referred to by interlocutors as the 'brown envelope'.[192] The brown envelope is imbued with huge symbolic value, in that it signifies a loss of time, and the imposition of unwanted procedures in which interlocutors have very little or no say, and whose outcomes are unknown and may have deleterious effect on their lives.[193] While waiting for their envelope, interlocutors often expressed deep apprehension that their application might be rejected or an in-person 'Work Capability Assessment' required. This assessment establishes whether, and the extent to which, an individual's physical or mental health affects their capacity to work, in turn determining their right to support. If they are awarded benefits, recipients must then be reassessed periodically to ascertain whether their condition or circumstances have changed since they were last monitored, and they are still eligible for support. The DWP increased the frequency of these re-assessments in the last decade with the stated objective of preventing people from becoming 'stuck unnecessarily in cycles of dependency' (DWP 2010). This policy has resulted in a significant number of claimants having their benefits reduced, modified, or cut altogether. Often referring to ESA assessments as 'sanity checks',[194] interlocutors bemoaned the fact that their state of mind is determined in a single, often quite short, appointment, especially given the volatility and long duration of much mental distress.[195]

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[192] For example, sometimes the assessment service requires claimants to attend an in-person appointment. The brown envelope is the generic governmental-issue standard envelope in which letters containing information about benefits, claims, and assessments arrive at claimant's homes

[193] This echoes findings from research on patients awaiting governmental services by others that identifies these processes as an expression of state control (e.g., Auyero 2012; Garthwaite 2013).

[194] The physical tests can involve, for example walking a short distance to gauge a claimant's locomotive skills and ability to hold their body in an upright position. Individuals who travel to the assessment centre by public transport are taken to have the capacity to travel for work.

[195] Interlocutors also expressed anxiety that Brexit might reduce Government funding for benefits and medicines. Two members of Fight the Power stockpiled medicines and baked beans, calculating how to live off reduced levels of both.

Activists commonly spend many hours strategizing about how best to present themselves in ESA claims forms and assessments and many to turn to others for help with these preparations. Some opt to open their brown envelope in the presence of others, a few even holding 'opening parties'. One interlocutor emailed his form to various activist groups, so that they could check that he had presented a robust case. Another drove fifteen miles across London to get 'moral support' and practical help with the form from a friend.[196] "It's so long and complicated, you have to be thorough, have an eye for detail, and be meticulous" she confided as she stopped off at my house on her way there. It took her three weeks to complete the form and even then, she was late handing it in, risking a sanction. Yet another interlocutor paid a subscription to an internet-based company that completes forms on claimants' behalf, (this company alleges that it has a 76% success rate (anon)). Requesting advice can result in long, complex debates about the appropriate wording for forms, or what constitutes 'evidence'. As just one example, Julie attached forty pages of notes to her form.

Interlocutors' difficulties with bureaucratic procedures are exemplified by one of Nadia's ESA assessments. Nadia is a sharp woman in her forties, a practicing Buddhist who is incredibly protective of her friends. She lives in a council flat with many plants. Nadia submitted her questionnaire as required and was upset when shortly afterwards her payments stopped. She received a letter explaining that she needed to be re-assessed and allocating her an appointment the following week. Given the short notice, she considered seeking a postponement to allow herself more preparation time. But she decided against this because she "didn't want to live with the stomach churning of waiting anymore". She emailed the FLL google groups asking if anyone was willing to accompany her to the assessment, to act as a witness. Janet and I offered to go and there followed a lengthy email exchange about what to wear, how to get there, what to take, how to keep records, etc. On the long taxi journey to the assessment centre Nadia was very tense, declaring that she needed to be as 'stress free' as possible that day. Her t-shirt sported a British Thyroid Foundation slogan, to remind the assessor that she has a thyroid condition and has already been approved for support by another organisation. She carried two large suitcases and a backpack containing recording equipment and a substantial collection of

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[196] There are also charities dedicated to helping people fill out these forms, although many interlocutors preferred the help of one another.

medical documents, tablets and prescriptions dating back many years.[197] When we arrived at the DWP centre Janet was standing outside talking to a man who introduced himself as Aki. Declaring that he had 'done the whole assessment thing', Aki explained that his wife had prepared an 'emergency package' for Nadia. He handed her a plastic bag containing packets of dried soup, pasta and sugar, tins of stew, and a jar of instant coffee, declaring that this was "In case your benefits aren't reinstated fast enough." He added, "And If you don't want it, perhaps you can give it to someone else in there who needs it", gesturing inside the assessment centre. He then left.

There was a long queue in the centre and many people were standing or sitting on the floor. Near the entrance was a broken water cooler; a post-it note stuck on it, reading 'apologies'. In the toilet, a half-drunk bottle of whiskey lay abandoned on the sanitary bin. Like Nadia, most claimants were supported by family or friends. Finally, Nadia was called for her appointment, which was to last a full 4 hours. It took the centre's technician half an hour to set the recording equipment up. However, it transpired that Nadia's assessor was deemed unsuitable, not having been trained to record interviews, so we were sent back to the waiting room.[198] We waited for a further thirty minutes until another assessor— Sophie (a nurse)—became free. Since the assessment centre was understaffed that day Sophie had been drafted in from Accident and Emergency Services. The assessment began, this time with a different tape recorder. However, the machine stopped recording only 6 minutes in. The technician set up a third recorder, though this too stopped working after only 10 minutes. The technician was called a fourth time, but after much consultation, it was finally agreed that Nadia could use her own recording equipment—providing she share a hard copy immediately with the assessor. By this time, Nadia had become agitated and, having repeated the introductory speech 4 times, Sophie seemed irritated. Already there was a level of wariness between them. Nadia started by explaining that, having 'flipped' and "gone mad" at her last assessment, she had been sectioned.[199] However, Sophie could find no record of this incident on the system.

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[197] It took her three days to source the equipment, which she borrowed from a local mental health activist group. The official DPW line is that they 'do not encourage the recording of appointments' due to the extra technical and staff delays, but Nadia made a case that she needed the recording, as she is partially deaf and also has trouble processing verbal information.

[198] Nadia had given the DWP advance notice that she wished to record the meeting, per the regulations, but the assessor had not received her message.

[199] The term 'madness' and phrase 'to be mad' have multiple meanings and uses among activists, including the common colloquial usage – to be angry. Due to her tone of voice and because Nadia went on to explain that she had been sectioned, I interpret her usage of the term as intended to mean both- mentally distressed and angry.

Sitting in the small, warm, cream and brown-coloured room with a hospital examination bed in one corner, Sophie asked Nadia about her many ailments, citing each one in turn, and repeating the same questions each time.[200] Initially Nadia's replies were long and considered. She explained that she does not use anti-psychotic drugs, even when prescribed them; nor does she rely on state treatments, preferring to manage her health difficulties herself using alternative therapies. However, as time went on, she became increasingly frustrated and her replies became curter. When asked why she had not seen her GP, she began to cry. She rationalised that NHS treatments do not work and make her "feel awful", indicating that she was "fed up with medical appointments and professionals constantly in her life." Sophie apologised for asking so many upsetting questions. But she was clearly required to consider all of Nadia's ailments so there was no let up. Next, Sophie asked to see Nadia's latest blood-test results. When Sophie declared the test results to be normal, Nadia, seeming offended, replied, "They're not normal! No... it's not *normal,* ... Without all my medications I would live for six days".

When asked how things were on 'an average day', Nadia sighed, "They fluctuate so much... one day I feel fine, another day I need to go back to bed three times". The GP had recently changed Nadia's anti-depressant prescription, without warning her that the drug might aggravate the irritable bowel syndrome symptoms she experiences. So, when Sophie asked if the new pills caused 'unwanted bowel movements', Nadia became confused. Sophie went on abruptly, "Have you every pooed yourself?" Nadia sighed and shook her head, telling Sophie that her kidneys were permanently damaged due to the lithium she had been prescribed for bipolar disorder and her temperature fluctuates widely following her thyroid operation. Sophie paused and, looking through Nadia's notes, nodded. Throughout the appointment, Nadia's head was sunken and her body slumped low in the chair. After many more questions, Nadia finally snapped, "I'm not going to get better, I'm not getting any younger, so why are you still checking all of these things?" Upset, Nadia then stood up to show us huge sweat patches under her armpits and around her thighs. She said, "It looks like I've wet myself" and asked for the air conditioning to be turned off. By about an hour and a half into the session, Nadia exclaimed, pointing at a DWP leaflet, "it says the appointment won't be longer than an hour and a half. You must have others, other appointments?" to which Sophie replied, "You've got a lot going on. We

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[200] These including endocrine problems, irritable bowel syndrome, asthma, calcium deficiency, kidney dysfunction, hearing loss adenitis, and bipolar, anxiety and thyroid regulation disorders.

have as long as it takes." We took a short break, during which Janet and I tried to comfort Nadia. We stepped outside the assessment centre for some air. Janet was angry, arguing that some of Nadia's health problems are 'not her fault' but caused by medications prescribed for other health conditions. Glancing warily at the centre entrance, Nadia threatened to leave, but Janet persuaded her to stay, pointing out that she would not want to go through this again.

In the second half of the interview Sophie's tone was very different tone. Before resuming the discussion, and speaking in a clipped voice, she instructed Nadia to answer concisely. She asked, "So, in 2001 you were diagnosed with bipolar. At the moment, is your mood up or down?" Nadia mumbled, "I am not living a normal life or a decent life, I don't see a bright future". Sophie then asked, "Have you ever tried to commit suicide?" Nadia did not answer but gazed into her lap, as though accepting defeat. From that point on she appeared to relinquish control to Sophie, who seemed intent on steering the exchange in a particular direction. She did so by posing leading questions—such as, 'do you find that your [medical condition] makes it hard to get through the day without resting?' This approach directed Nadia to give 'yes' or 'no' answers, without elaboration. The final question was, "and how long do you think it will take you to get over this appointment? "Hours? Days?"—to which Nadia replied, "Months". When Sophie finally switched the tape recorder off the relief in the room was palpable. Making it clear that she was not allowed, officially, to impart this information, Sophie explained that Nadia's benefits reassessment claim should go through unchallenged, and that in fact there was enough evidence for Nadia to 'pass' based on her medical notes alone—meaning that an in-person assessment had not been necessary. Exasperated, I asked Sophie why she had not explained this sooner, saving everyone hours of anxiety. Sophie replied simply, "We had to ask you about everything because it was being recorded". Turning to Nadia she continued, "I tried to stop you talking yourself out of support." And then asked, "They usually do psych assessments over the phone to avoid people having to come in; perhaps you didn't know this? It might be because you aren't seeing your psychiatrist, because you've chosen to come off meds now …for some years?" To which Nadia mumbled something about not any longer 'being in the system'.

Nadia's ESA assessment illustrates how the use of prescribed protocols can cause service-users confusion and distress. Unlike Andy, who continuously challenged the assessment process, Nadia co-operated. Knowing her to be a fiercely independent person

and an active mental-health campaigner, at first, I found her acquiescence surprising. It seemed as though the assessment had brought her sense of self into question—that she was caught between two contradictory subjectivities. Reconciling distinct and competing concerns appears to have resulted in a personal struggle; one moment Nadia expressed her vulnerability and lamented her numerous health difficulties, and the next, she downplayed her ill-health, rejected treatment and emphasised instead her self-sufficiency in managing her condition.

The standardised procedures applied in eligibility assessments do great disservice to the intricacy and ambiguity of interlocutors' everyday experiences of mental distress. Patients are forced to categorise and quantify their state of mind in 'non-ambivalent' ways, wherein, as Bruun explains (2019; 163), "subjectivity itself is transformed into an object of scientific observation". Thus, Nadia's moods were recorded using a simple 'up' / 'down' binary, and her symptoms 'averaged out', when in fact both her symptoms and moods are highly variable. Moreover, the procedures are not designed to deal with patients who present complex health problems, which in Nadia's case include a mix of physical and mental ailments. Considering each ailment in turn made it look as though Nadia's conditions are distinct when in fact their symptoms, treatments and impact interact. Nadia struggled to explain that the various ailments aggravate each other, her state being further exacerbated by the side-effects of numerous medicines. The more Nadia tried to describe her experience, the longer the appointment took and the harder it was to assign her entitlements correctly, this reducing the chance that she would receive the support needed. When Sophie used words such as 'normal', Nadia responded by emphasising the severity of her illnesses, to justify her claim for support—but this diversion did not help. Eventually, Sophie took control of the appointment, insisting on conciseness and framing the questions in such a way that Nadia's answers would satisfy the assessment criteria. Nadia experienced the assessment as extremely stressful, apparently to the point of making her ill. She was unable to eat or sleep properly for days beforehand and 'crashed' for days afterwards. And yet, after we left the premises Nadia said, 'I knew it would be fine, I just didn't know what I would have to do to get there'. The level of anxiety she displayed in the days prior to the appointment suggested to me that, in fact, she had not known that it would be fine. Even if she had, her *not knowing how to get there* still implied a high level of insecurity about the process. The next section argues that these kinds of difficulties, stemming as they often do from cumbersome bureaucratic procedures, are

frequently aggravated further by the modes of communication adopted by assessment staff.

3.5 Resisting coherence

According to NHS guidelines, communication and partnership between mental-health professionals and patients are key to the development of effective care plans in mental healthcare. However, the evidence I present in this section demonstrates that, in the case of individuals diagnosed with serious mental-health conditions at least, patients have little or no say in their diagnosis or treatment. This is partly because managerial requirements around efficiency and accountability in clinical encounters greatly impede communication between clinician and patient, rendering partnership impossible. Communication challenges are evident in the sessions with Andy and Nadia. Clinicians use 'closed' body language and non-verbal signals to control exchanges with patients, this preventing in-depth discussion and ensuring a focus solely on immediate, instrumental objectives. By avoiding eye contact and physical proximity during appointments, certain messages and ideas are articulated and conveyed, not simply through language, but also through the body.[201] Not only do these modes of communication exclude patients' own perspectives, but the reliance by clinicians on the biomedical model in diagnosis and treatment is perceived by interlocutors as an intentional act of silencing.

'Are you feeling optimistic about the future?'

During fieldwork I heard frequent complaints that clinicians—GPs, psychiatrists, mental-health nurses and others working in the mental-health system—are quick to reach diagnoses, most often ignoring the experiences and perspectives of those affected. Several interlocutors even claimed that clinicians sometimes diagnose and decide on treatments prior to assessing patients. Communication failures in clinical encounters are central to these concerns. I have shown that communication problems were a major feature of Andy's care coordination appraisal. In this section, I make clear that these problems were evident even before the appraisal took place, setting the tone for all that

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[201] This evidence confirms research by others (c.f. Janine et al. 2018).

was to follow. His GP surgery called one day to say that he needed an urgent appointment, without explaining why. Andy had stopped taking his medication at that point and feared that when his GP found out he might section him.[202] However, it transpired that the appointment was simply to check his medication dosage, a question that could not be asked over the phone due to patient confidentiality.[203] Andy told me that waiting to find out why he needed an appointment had nearly sent him 'over the edge', causing him many sleepless nights. For this reason, he asked me to be present at the care coordination appraisal to provide moral support and take notes.[204] In the run-up to the appraisal Andy sent copious emails to all of those who were due to attend, outlining the issues he wanted to cover.

On the day of the appraisal Andy was extremely agitated. While we waited at reception a man approached us and introduced himself as Ken, without explaining his presence. Andy was distracted—gazing elsewhere—and we stood in silence until Andy was finally called. [205] We waited for some time in the appointed room before a man I took to be the psychiatrist entered. Without looking at us, he said, "Oh. [Name] isn't here. I'd better go and get her" and promptly walked out again. We waited ten more minutes. Still not understanding why Ken was present, I asked him about his work. He replied, "I'm a floating support worker, mainly since community mental health teams closed down". The psychiatrist eventually returned, followed by a woman (who was not introduced, and I later discovered was the care coordinator) clutching a clipboard. She sat down without greeting us. The psychiatrist opened his laptop. Staring at the monitor, he nodded in my direction, and asked Andy, "Who have you brought with you this time?" Andy replied, with a hint of pride, "Keira's an academic, an anthropologist". The psychiatrist gazed at my notebook, and I worried that he might tell me to stop taking notes. Looking back at his computer he said, "Shall I put, 'a friend' then?"—and Andy nodded in assent.[206]

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[202] Andy is trapped in a perpetual cycle as he prefers not to be on medication but is often sectioned when not medicated. He is currently on a clinical trial widely criticised including by psychiatrists that is focused on weaning people off medication.

[203] The psychiatrist had accidentally prescribed Andy a dosage much higher than the recommended daily amount- so Andy was technically 'overdosing'.

[204] He later revealed that he had hoped that my presence would prevent him from being sectioned.

[205] The receptionist used a name I did not recognise Andy by. Often employed as a safety measure to protect their anonymity, many activists have several names

[206] Andy had emailed the psychiatrist prior to the meeting asking if I could attend and the psychiatrist had given his consent. However, the psychiatrist appeared to have forgotten this, or was double-checking. A cynical way of interpreting his psychiatrist's decision to document me as 'friend' could be that it was yet another way that Andy's complex reality is reduced by the clinical environment.

The session lasted over forty minutes, and yet the exchange was uncomfortable and disjointed throughout. As with Nadia's ESA appraisal, the questions were drawn from a standard list. Unlike Nadia, though, Andy seemed intent on challenging the process, continually shifting the topic of conversation, sometimes by throwing questions back at the psychiatrist. He refused to give straightforward answers, and instead often resorted to speculation, rhetoric and abstraction. The following exchange is just one example;

> Psychiatrist: … You know when you were very unwell, all those years ago, do you think there is the possibility of it happening again?
>
> Andy: Yes, it's possible any time. Anyone could go at any time. You could go psychotic, doctor. It's hugely important that when you're on the verge, you need people to be honest with you.

The psychiatrist was referring to Andy's hospitalisation under section. Andy sought to divert the discussion away from this episode. By emphasising the unpredictability of psychosis, the possibility that anyone can be affected and the importance that others help by being honest, he somehow seemed to be absolving himself of personal responsibility for his state of mind. His allusion to the fact that anyone could potentially experience psychosis may also have been an exercise in bringing the psychiatrist closer to his personal subjectivity—thereby bridging the divide between them. Andy's reference to the need for honesty likely reflects concerns by activists that psychiatrists and other clinical staff conceal information from patients on the pretext that confidentiality is required by the regulations (or, as Mike put it, 'covering their backs').[207]

The psychiatrist attempted to vary his tone of voice while questioning Andy; even so, it was apparent that he was reading from a list. And when Andy challenged him, rather than responding directly, he simply changed the topic, as in the exchanges below:

> Psychiatrist: Are you feeling optimistic about the future?
>
> Andy: Climate change is a real threat to humanity, wouldn't you agree?
>
> [The psychiatrist blinks]
>
> Psychiatrist: You're not going to die from it right now…
>
> Andy: You don't believe it's a threat to humanity, so we'd disagree.

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[207] See chapter 2 for a discussion of the NHS as an accountable bureaucracy.

[The psychiatrist jots something down on his computer and moves on to new topic.]

In another example,

Psychiatrist: You said you wanted a specialist in Asperger's?

Andy: We prefer the term neurodiversity

Psychiatrist: How about 'high functioning autism?'

Andy: No, neurodiversity. You have a great learning curve ahead of you, doctor….
I appreciate you may not be up to date with the latest information and terminology.
Why is there always a psychiatrist in these meetings anyway?

Psychiatrist: You haven't had meds in quite a while

Andy: You know I'm not on meds because I'm on [*trial for the reduction and withdrawal of anti-psychotic medicine*]

The latter exchange is one of the clearest instances in the assessment where Andy expressed his contempt for psychiatry. This was indicated by his refusal to conform to the psychiatrist's language, his attempts to question the psychiatrist's expertise by instructing him on the meaning of various technical terms, as well as his disdain towards the questions put to him and refusal to answer them as the care team expected. At every opportunity, he pointed out what he perceived to be assumptions, flaws, and inconsistencies in the enquiry. Meanwhile, the psychiatrist strove to stick to his script[208], possibly to reassert his authority and ensure the assessment did not get derailed. An example of this was when he ignored Andy's criticism and turned abruptly to matters of medication, this being an area in which he has a monopoly of expertise.

Avoidance of eye contact is also a marker of the team's communication style. The psychiatrist's eyes remained fixed on his monitor throughout the appraisal, while the care coordinator stared continuously at her clipboard.[209] Avoiding eye contact permits clinicians to construct 'boundaries' so as to separate them from their patients, a strategy that reduces the time required for appointments (Marcinowicz et al. 2010). In this particular case, it is not clear whether the psychiatrist was trying to manage time pressures, or his tactic (conscious or not) for dealing with Andy, who is likely regarded as a 'difficult'

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[208] 'Are you feeling optimistic about the future' is a question included in the WEMB scale, a standardised questionnaire used to measure mental wellbeing.

[209] I observed she did not look at Andy or I for a full 20 minutes.

patient.[210] Either way, while avoiding eye contact may enable clinicians to meet quotas set by management, studies of GP appointments have highlighted how it can be a source of distress for *all* parties involved. For GPs required to avoid emotion-talk in the interests of brevity, it can result in interactions with patients that they find unsatisfactory. From the patients' standpoint it signals that the clinician is interested in neither them nor their health.[211]

The team's very formal and distanced communication style merely added to the difficulties in the appraisal that arose from the use of pre-determined questions and from the psychiatrist's failure to engage meaningfully with Andy on issues that mattered to him. All these factors together made the 'collaborative partnership', as required in care planning, difficult, if not impossible, to implement. It was not clear whether Andy was trying to usurp the process or negotiate with the team to receive better care but his manner of engaging with them only made matters worse. In fact, far from achieving its bureaucratic objective of revising his care plan, arguably, the appointment (and Andy's discomfort with it) merely increased the complex difficulties he was facing.

Re-telling and silencing realities

Another significant communication shortcoming raised by interlocutors in relation to health and social welfare procedures is the difficulty they face in accessing their medical records. Their main concerns are that they have no idea what information about them is held in these records; nor do they have a right to change the records. Yet, it is also true that reading one's records is not necessarily experienced positively and can have unforeseen adverse consequences. Steve requested to see his notes and was both confused and upset by what he saw. His recollection of events differed markedly from the account given in his notes—indeed, he complained that they contained details of "things that did not happen".[212] For example, the notes described him as 'aggressive', when all he remembered was feeling scared and helpless. "I read my notes and I see different versions of myself on paper", he

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[210] This may also have been due to other issues I learnt about after the appointment. Andy made highly problematic comments to one of the nurses, complaining that the two of them were so different that they could not communicate properly or relate to one another. Since she was of Afro-Caribbean descent, she interpreted his remarks as racist.

[211] Not being examined, or even looked at properly, is something also raised by family members of sick patients in Papua New Guinea whilst doctors tend to their relatives, demonstrating that this concern is not unique to the UK (see Street 2014)

[212] Using the Freedom of Information Act (2000) some activists request access to their records, including psychiatric reports written following sectioning—although not many are shared freely.

complained. "People [hospital staff] paraphrase you in harmful ways. It's obvious that people are just trying to cover their backs. This is a re-telling of the truth, and no wonder, because they [the staff] fear being dumped by their managers and losing their jobs".[213] Steve asked that several changes be made to the notes, so as to take his perspective into account. But his request was denied. Steve was not the only interlocutor to raise concerns about what, in their view, is the 're-telling' of truths. One interlocutor was upset that he had only discovered what nursing staff really thought of him, when, during his tribunal, they presented documentary evidence substantiating their argument that he should remain hospitalised under section. Similarly, Bryan, a kind and polite Irish man in his fifties, expresses a deep distrust of the mental healthcare system and the people working in it; anxious to prevent information about him being shared between the Department of Psychiatry, pharmaceutical companies and his GP, he changes his email address and mobile phone number regularly. He told me that he remains alert to breaches at all times, searching for 'what's going on underneath', and looking for 'dodgy' connections between people, institutions and systems.[214]

Acts of silencing by mental health professionals are often interpreted by activists as intentional. Clare, who had been sectioned, asserted that hospital staff had failed to respond to her anxieties. She posed a rhetorical question to SAP members, asking whether nurses, "*try* to make you paranoid", this being their way of legitimising decisions to keep patients in hospital. Leo replied in a sarcastic tone that he has, "positive paranoia' – I think staff are helping me". His joke caused much amusement, revealing that for activists the idea that clinicians might *want* to help patients is absurd. There were claims that mental-health professionals sometimes use bureaucratic red tape to disguise or excuse clinical failings. In one email thread Janet asserted that, "The police managed to lose the statement I gave about my mother abusing me. They never interviewed her even... the subsequent cover-up and being disbelieved by psychiatrists about the abuse is worse than what happened originally". Amir replied to her, saying;

> It's all too easy to call people like us paranoid but I am very familiar with what has
> happened to you--the lies and the cover-up and I truly empathise. When I tried to

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[213] Medical Anthropologist Ashe has written about medical notes as the "fixing in truth…a particular narrative of fact" which "reenforces the doctor's privileged position" (Ashe 2021; 260).

[214] Often, these connections we re-affirmed; for example, there are levels of connectedness between all of these institutions if one looks hard enough. For example, the head of the Department of Psychiatry's brother works as a CEO for a large well-known pharmaceutical company.

get my old files from psychiatry and social services, it took ages and even after much persistence, no definitive answers. I asked if they had my files and, instead of saying yes or no, they kept saying that 'it's council policy to destroy files after 25 years' if there's been no further contact. So, I asked, is mine destroyed? They wouldn't answer. Another tactic was to send me to other departments or offices to get a response - who often sent me back to them! (Amir, email)

The incident described by Steve and the exchange between SAP members make clear that the way communication is managed by health professionals can serve to intensify, rather than reduce, patients' sense of insecurity. However, thinking back to Andy's care coordination assessment in particular, I would argue that not all interactions with clinicians are straightforward examples of structural violence or defeat, in which subjects exert power over other subjects, so much as a negotiation between two parties in which the Andy actively resisted the authority of the psychiatrist in particular. Power dynamics do not work as a simple dynamic of 'control versus resistance' (Knights and Willmott 1990). Nor does power operate unidirectionally from the top down, but rather in a more complex, dynamic manner.[215] Andy disrupted the standardised questions and 'routinised intimacy' of the appraisal (Armstrong 2016) by engaging in numerous small but meaningful acts of resistance (Scott 1984), deriding the team's professional expertise and attempting to undermine their knowledge and authority throughout. However, in resisting, Andy prevented the meeting from reaching a satisfactory conclusion, leaving him in limbo—without the support he craved. Given that bureaucratic regulations are also a barrier to service-users accessing their notes, communication challenges can similarly be seen as increasing interlocutors' sense of suspicion and mistrust—to the point that the motives of mental health and other staff are questioned, and interlocutors became convinced that often staff are acting primarily out of a desire to protect their jobs. Thus, interlocutors find themselves in the ambiguous position of needing and depending on a system that they regard to be both necessary and also highly detrimental to their mental health.

3.6 Chapter conclusion

"Out of hours services, that's my quality of life"

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[215] Jupp notes that activists tend to be portrayed either as agentic heroes, or marginalised victims (2022; 58).

In this chapter I explored interlocutors' experiences and perceptions of the therapeutic and social welfare provision delivered by the NHS and DWP. I showed that they regard this provision as being seriously remiss. In making this case, I concentrated mainly on the evidence generated by two assessments, as well as other views and activist accounts more generally.

According to interlocutors, NHS and DWP procedures focus on accountability and self-management goals rather than patients' wellbeing; how they feel about or experience their distress. They complain that clinicians have neither the remit nor the inclination—nor even the time—to consider the more complex, existential anxieties they grapple with. Instead, clinical diagnoses are oriented towards immediate concerns, principally the patient's functioning, as measured against a standard list of medical symptoms and behavioural attributes, such as planning, reliability and self-discipline. This mode of diagnosis is experienced by patients as a denial of their reality. Consequently, for the most part, they regard their contact and human connections with health professionals as anti-therapeutic. Thus, the relational landscape of 'TAU' is experienced as lacking, and at times, harmful. Despite a policy emphasis on efficiency, communication and partnership, the intransigence of NHS and DWP bureaucratic accountability procedures make matters worse. The differing understandings and expectations of mental distress and around clinical encounters are evident in the two case-study assessments described in the chapter. Clinicians need to obtain certain information from patients, and patients need certain information from clinicians. However, their information 'needs' are not the same—they are not even complementary. Clinicians deem interlocutors' perspectives untrustworthy and vice versa, such that the two sets of viewpoints are often in conflict. As a consequence, much of the discussion in the assessments centred on assigning rights, responsibilities and blame, and settling on the correct procedures, rather than identifying and agreeing appropriate treatment and benefits. The clinicians absolved themselves of personal responsibility for any deficiencies in the process by pointing to the constraints imposed by institutional regulations. They also highlighted patients' shortcomings—such as Nadia's failure to keep herself informed about the correct procedure for ESA assessments. Conversely, interlocutors assert that accessing appropriate care and support is their right, so that when Andy found the provision on offer failed to acknowledge

his true needs, he became conflictual. Rather than seeking to agree his care plan, he focused on criticising the system, those working in it, and psychiatry more generally.

I showed through exploration of these encounters that the discrepancies between service providers and service-users is not merely a rhetorical matter but also has a vital experiential dimension, which is keenly felt by interlocutors. Clinicians may have little alternative other than to resort to sectioning and involuntary hospitalisation of patients and are likely to believe that in doing so they are acting in the patients' best interests. However, interlocutors provide vivid accounts of the harm engendered by these encounters, their recollections of the violence and silencing involved destroying their trust in services and service providers as well as overshadowing their experiences in the present. Thus, clinical encounters often compound rather than ameliorate interlocutors' ill-health.

As suggested by Bruun (2019), these findings raise important questions about the subjectivity of individuals caught up in these kinds of complex, challenging circumstances—questions that apply to both service providers and service-users. Interlocutors are trapped in a paradoxical situation whereby they seek and need support whilst at the same time disagreeing with both the rationale behind that support and the form of support provided. Despite small personal triumphs, activists feel comparatively powerless in determining the outcome of clinical encounters, which leaves them with a deep sense of apprehension and can affect how they perform in these encounters. This is especially evident when treatment is experienced as more detrimental than beneficial, as in the case of Andy, who rejects his psychiatric diagnosis whilst depending on a system that uses this diagnosis to justify giving him support. Individuals in this position are forced to go along with being classified as 'mentally ill' through scientific criteria, even when this label does not fit with their self-perception; hence, for example, Nadia's efforts to perform her distress according to the clinicians' expectations. Andy appeared far less compliant in his assessment than Nadia did in hers, and in fact his resistance thwarted the whole process, leaving his situation unresolved. However, his investment in the exchange was evident as both before and after the meeting he expressed considerable concern about the likely outcome.

This brings me to the core argument of the chapter, which is that the conceptual distinction between the biomedical model and activists' understandings of mental distress is irreconcilable. This circumstance creates an epistemic and phenomenological dissonance

that undermines choice and connections between persons and also embeds and enforces barriers between service providers and service-users. Will's observation that "As if by magic or mental gymnastics, words like help or support take on a different meaning when it's medical practice" highlights that it is not just activists but also clinicians who are impacted by this situation. Embedded in Will's remark is a thoughtful and complex commentary on the conduct of mental-health professionals. He was referring to the hospital nurses who forced him to swallow an anti-psychotic drug. While the emphases in policy may be on communication and partnership, the nurses' understanding of what partnership means is very far from his own. Will found their use of physical restrain—and their insistence that they were doing so for his own good—hurtful and humiliating, the invasiveness of their actions feeling to him "like rape". For Will's part, in resisting treatment, he was trying to communicate both his distress and his right to refuse medication.

By referring to 'mental gymnastics', Will was indicating that clinicians must bend concepts such as 'help' and 'support' to meet their own ends—which in his view are primarily about ensuring that patients remain calm and compliant. The phrase 'mental gymnastics' implies that this 'bending' takes some effort, as it involves a degree of cognitive discord and potential denial of empathy towards patients. His reference to 'magic' implies that in his view, the nurses were somehow disconnected from the situation, refusing to accept responsibility for their actions. He said it was as though they were under the influence of some external force. Because Will felt brutalised by their actions, he struggles to acknowledge that health professionals have a commitment to patients' wellbeing. Though clinicians follow diagnostic and treatment templates that are very familiar to them, activists describe these templates as 'irrational', and argue that they 'do not make sense'. Thus, in such instances, there is no shared understanding of mental distress or support to draw on. For these reasons, patients and clinicians are neither able to fully trust each other nor communicate effectively. Consequently, the mismatching of expectations surrounding bureaucratic and therapeutic procedures and encounters cast a long shadow over interlocutors' live

Chapter 4: Building Healing Spaces in 'Any' Place

Vignette

Bryan and I are sitting, chatting absent-mindedly, in a pop-up mental health service-user café in central London where we often convene, sometimes with others. A sign on our table reads 'reserved' and we realise that we have accidentally taken a table intended for the local NHS wellbeing centre. Each week, a representative from the centre sits in an allocated spot, providing a drop-in service for people to discuss mental health support options in the local area. I become nervous that people will start 'dropping in' on Bryan and I. One of the café managers sitting at another table is staring at us, and, making to leave, we sheepishly joke that, "We have come to *be* the [wellbeing centre] and help people. But we need to find out what wellbeing actually *is* first". She dismisses us with a wave of her hand and gestures for us to relax and sit a while longer. With a smile and a wink, she says, "Between you, I think you've got what it takes".

4.1 Chapter introduction

In chapter 3 I explored interlocutors' experiences of NHS mental-health treatments. I made clear that mental-health activists seldom consider these interventions to be therapeutic; far from it, treatment has left many with high levels of fear and distrust.[216] There are myriad reasons for this, including the perception that clinical settings are unsafe and clinical relationships uncaring and judgemental. Activists draw attention to the negative experiences of treatment which divest them of any sense of individuality or control over their lives. I argued that these perceptions are due, in part, to the fact that clinicians and patients draw from different conceptualisations of distress this dissonance, leading activists to experience a strong sense of epistemic violence and injustice. There is also the fact that welfare benefits are conditional on compliance with what interlocutors take to be invasive treatment regimes.

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[216] Indeed, it has been suggested that the processes of criminalisation, hospitalisation, and institutionalisation commonly associated with mental ill-health can drive people into "moral breakdowns" (Zigon 2007; Myers 2019).

Drawing on observations of activist events as well as exchanges with interlocutors in pubs, cafes and homes, this chapter is the first of three which explores activists' modes of healing. At first glance, activists' ways of healing seem surprising, not least because they appear to challenge several key assumptions in the psychotherapeutic literature about what it takes to cure mental ill-health (c.f. Andrews 2017; Bell et al. 2018). This literature generally assumes that treatment depends on the input of practitioners with specialised training and expertise in mental health. Likewise, recuperation is believed to be facilitated by locating treatments in environments designated specifically for that purpose and by following established routines and procedures that are confined to particular moments in time. However, for activists, the healing process does not rest on therapeutic relationships conducted at appointed times in assigned locations.[217]

Rather, I will show that activists practice *non-attachment to places*, undertaking healing in cafes, supermarkets and the streets—seemingly without a care as to who overhears, or observes. In doing so, activists make a transformative mark on their environments; building their own healing spaces by 'being and acting relationally'. In Zigon's (2021) words, it is what happens 'between' activists that counts. Acting relationally means engaging with others in ways that are consistent with certain values. It involves the continuous construction, negotiation and 'living out' of ways of being that centre, above all, on respect for the autonomy of individuals and compassion for others. In the chapter I provide examples of the multitude of ways in which these values are expressed at activist events and in informal interactions, focusing particularly on the attentiveness shown towards interlocutors' personal narratives of suffering and ways of being together. I suggest that adherence to these relational practices proves an individual's integrity, and in so doing reinforces their sense of personhood—these attributes being considered by activists as vital for healing.

In this discussion I adhere to a particular understanding of *space* and follow the anthropological literature in distinguishing space from 'place' (c.f. Eyles 1995; Myers 1986; Weiner 1991; Feld and Basso 1995; Hirsch and O'Hanlon 1995; Ingold 1996). I use 'place' to refer to specific locations and deploy the concept of 'space' to emphasise how activists build worlds *across* diverse locations; their peripatetic disposition and mobility around

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[217] Many scholars (e.g., Moon et al. 2006; Evans et al. 2009; Laws 2012) have pointed out that conventional therapies (and biomedical mental health treatments more generally) are spatially focussed, or in other words, are practiced in particular places and locations.

London is reflected in their assemblic, networked relationships. At the same time, by deemphasising place activists are rejecting specially designated 'therapeutic' places. In my understanding, spaces do not have 'inherent' therapeutic qualities—such as is argued in the classic literature on therapeutic landscapes (see for e.g., Gesler 1992; 2003 5). That literature contends that certain locations, such as the therapy room, or a park, are imbued with therapeutic qualities or 'healing potential'.[218] However, activist healing practices stretch across multiple spaces, many of which do not have symbolic therapeutic value. I use 'space' also to convey the idea that the shadows of biomedicine and welfare not only reside in specific places, but also bleed across all spaces. Understanding space in this way aligns with phenomenological notions of space as lived and experienced (Merleau-Ponty 2002). In particular, it implies that space embodies the "capacity of all social relations; it is what people do, not where they are" (Jiménez 2003: 140).

Activists' healing spaces involves space-*making*. The therapeutic potential of spaces depends on a multitude of relational elements. In the case of activists, the historical context of locations that are rooted in activism and subversion is important, as are the actions and relationships constitutive of activist networks. For them, London is a product of a variety of interventions and movements (Ingold 2011) and is always in the process of being made (never finished nor closed) and reflects the co-occurrence of simultaneous stories 'so far' (Massey 2005; 5). Healing spaces are located in-between people, but unlike some phenomenological conceptualisations (e.g., Ingold 2011), they are not purely experienced through consciousness or embodied perception but also as a product of politics, power and history. Hence my use of Zigon's (2017) concept of worldbuilding, which recognises the dynamic relationship between people and spaces and allows for different conditions of existence, or different ways of being in the world. It also recognises that relational practices may transcend social boundaries and geographic locations. Finally, it invokes affect and intentionality, as Johnson prompts, "considerations of space and place in medical anthropology should not be understood as mere context" because "space-holding is also part of healing" (2019; non-paginated). Writing about a collective of healers of colour who work toward sustainable black lives and healing justice in the

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[218] Williams (2007; 207), for example, writes about, 'therapeutic landscapes' as "spatially delineated areas with 'health-enhancing' properties". I do not deny that certain places (such as 'green' and 'blue' spaces) have been demonstrated to enhance actors' wellbeing, but this was not a relevant for my interlocutors. There is a movement in the NHS to make hospitals more user-friendly and architects are consulted on colour, shapes and other design features with the intention of making them more restful, reassuring etc. However, I argue healing is about active engagement with making place and not just passive use of places designed by others, however well-designed they may be.

USA, Johnson describes how healers 'guard and hold' space from colonial, white energy;[219]

> They [healers] carry place with them as an embodied assemblage of knowledges, experiences, and subjectivities gathered from respective sites of practice. Place travels in this way as a series of occurrences… […] … It is a radical exercise of sovereignty on the part of the healer to assert that "this space is ours", that "our bodies are ours", and to fortify Black communities from potential harm against the body by way of the micro-aggressive behaviours of the well-meaning… […] … this is a kind of preventative healthcare (Johnson, 2020; non-paginated).

In different ways, these authors understand social positioning and lived experience as central to spaces; space is produced through experience, social relationships, and interactions between persons and institutions. In this view, spaces help subjects make 'sense' of the world in a way that consolidates feelings of identity and belonging. Thus, activists 'make' spaces in which they feel belonging through certain ways of being.[220]

In the first section of the chapter, I explore how activists create healing spaces. I note that the spaces activists use intentionally for gathering seldom have the kind of features conventionally associated with therapy. However, many have a long history as sites of political engagement, and I therefore reason that they are an important manifestation of activists' core values. There is a certain ambivalence among activists between wanting to use certain places because of their socio-political/ cultural significance and practicing relational practices *outside* of particular spaces—as a way of *reclaiming* space.[221] For activists, locations acquire meaning as therapeutic spaces not through their physical characteristics but through relational practices that are intentionally centred on 'being-with' others. In section two I explore activists' relational practices in greater detail. I argue that despite sharing certain values and adhering to certain social practices, activist organisations do not form a coherent community. Rather, activists' social worlds are

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[219] She describes the healing collective as "a gathering space where people are invited to tend to the needs of their individual, social, and political bodies, which are constantly intermingling, dissociating, and coming back together again" (2019; non-paginated), the fluidity and connection being evocative of mental-health activists' ways of being.

[220] See Jupp (2012) for an account of how affect is central to activists' sense of belonging.

[221] It is important to note the historical continuities between mental-health activist networks and the Occupy movement – which was a distinctly spatial exercise, particularly in regard to 'reclaiming' spaces associated with trade and capitalism (such as the Stock Exchange in London and Wall Street in New York).

comprised of extremely diffuse and informal networks whose underlying ethos of 'being-with' others is one of permissiveness and inclusivity. This means that whoever appears at activist events is accepted and allowed, even encouraged, to participate—and to do so on their own terms. Participation often entails narration of individual testimonies of distress, hope and struggle, these testimonies commonly being the driving force in activist gatherings. Given the attention activists award to these narratives, listening is also found to play a vital role in their relational practices. Consequently, in section three I examine activists' attitudes towards and modes of listening. I maintain that listening has been neglected in the literature, and go on to consider the social, political and cultural dimensions of this important form of interaction. I suggest that activists instil listening with particular meanings, affects and embodied behaviours. Listening acts require considerable patience and are performed in particular ways, with compassion and without censure. As a consequence, listening is granted high value by activist groups and confirms the listener's worth. In this way, listening acts can be seen as central to the healing process.

4.2 Assemblic space-making

In this section I investigate interlocutors' engagement with physical spaces, focusing particularly on the sites they use for social and political events. I maintain that interlocutors' relationship to space is not always random. Though the venues frequented by activist groups are often very run-down and unwelcoming—even 'hostile'—they are far more than mere physical locales. Activist spaces offer an important sanctuary for those seeking to escape what they perceive as an unjust and harsh health system. Many are public spaces, some with a long history of hosting local activist events; others are primarily used because they are donated for activists' use. I suggest that, as venues where activists are freed from oppression and able to build alternative social worlds, activist spaces are endowed with "ideological, symbolic, and political meaning" (Bourdieu 1989: 510).

Activists gather frequently, whether weekly, monthly or intermittently, these occasions providing them with an important opportunity to get together in one place. In addition to meeting up with individual interlocutors on an *ad hoc* basis, I attended many of these events. In doing so, I learned that activists do not seek continuity of spaces, their networks being highly mobile and spanning multiple sites. In addition to a number of regular venues,

we met in interlocutor's houses, as well as outside hospitals and in parks depending on weather or mood—these latter locations being accessible to the general public. RMH is the most peripatetic of the groups and meets throughout London, choosing the place and time according to members' needs at a particular point in time. Even so, despite the variability of locations used, the choice of sites often seemed somehow deliberate. For instance, one day, RMH decided to organise a community picnic in a park in central London. A mixed leisure and campaign event, the hope was that it would allow people to relax and socialise in the July sun, as well as raise awareness of the tyranny of workfare. They called it 'Picnics are a health outcome'; a satirical play on Public Health England's phrase 'Work is a health outcome'. The group spent many hours discussing a suitable location, taking into consideration the different accessibility and mobility requirements of the attendees. The picnic had to be positioned close to tube exits, bus stops and public toilets, but also needed be in a location where it would not attract the attention of the police or park authorities, as the group feared it might be shut down. Other significant locations included a public garden outside one of London's largest psychiatric hospitals (see photo below) where SAP sometimes hold parties for inpatients[222] and a café in large north London shopping centre.[223]

I sought to understand what informed activists' location choices. Most of the regular events I participated in were held at four sites that are used particularly frequently by activists. Two of these sites are social centres rented jointly by a variety of local groups and two belong to wealthy property owners with leftist political leanings.[224] Given the high cost of property in London and activists' constrained material circumstances, affordability necessarily plays a part in their choice of meeting spaces, all of which are located in the

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[222] Some patients come supervised, but others sneak out without supervision, depending on their sections.

[223] The café is known as being "open to anybody", and mental health service-users/survivors meet there from about 2pm until about 10pm on Tuesdays. It became a meeting place for activists after a well-liked mental health service-user died unexpectedly, as friends would gather there to mourn his death. The people who now use the café are not necessarily part of the original group. Their intention (as explained by Bryan) is to create a kind of casual 'drop-in'. Some come with specific queries, such as seeking advice on paying bills, claiming benefits, or medication, and others come to socialise. The arrangement is by intention very informal. There is no correspondence or social media about these gatherings and interlocutors simply turn up.

[224] SAP convene in a disused function room in a run-down pub in central London. FLL meet at a small Victorian primary-school-turned social hub in East London, which also hosts other 'therapeutic' groups, such as the *Co-Counselling Union*, and the *Children of Alcoholic Parents* support group. (See photos, at the end of this chapter). RMH meets all over London.

capital's poorest areas.[225] However, it soon became apparent to me that the choice of location is about far more than simple cost. Many activist venues are also used by local grassroots groups as important sites of local gathering and organising. They are generally run according to anti-establishment (or 'commoning') principles (as described by interlocutors). [226] Essentially, this entails co-organisation and ownership, with responsibility for maintenance and upkeep shared by different user groups. Groups applying to access these spaces must agree to perform a role in the community that aligns with the values and political objectives shared by all users. For example, groups occupying one of the East London hubs, a flat in a residential block, are expected to; 'understand the importance of taking care of ourselves and each other whilst struggling against the social, economic and environmental injustices created by capitalism and the oppressive forces that come with it.' (Common House 2020). The flat is an oasis in a busy London borough. The walls are coated, floor to ceiling, with a huge collage of posters and leaflets advertising demonstrations, events and meetings, along with body-positive zines, and union and sex worker's rights posters. It is used and cleaned on a rota system by several collectives[227] and is also equipped with kitchen and shower facilities for those without adequate amenities in their accommodation or who travel long distances to attend meetings.

However, despite the strong commitment to these communal premises and assumption of collective responsibility for maintaining them, arriving at a new site could be nerve-wracking. Located typically in run down areas where one would not normally choose to linger, activist spaces are frequently neglected and unwelcoming.[228] Most groups use sites that are anonymous, even invisible, to the unsuspecting passer-by since they seldom have a sign, official entrance, or any other way of signalling their existence. They are generally only evident to those who are 'in the know' or have been invited to participate in an event. Unlike other organisations using these venues, activists tend not to display any

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[225] Socioeconomic maps of London's boroughs indicate that Tower Hamlets has the highest rate of co-morbidities and unemployment in London. Activists often live in places characterised by social inequality and residential segregation.

[226] Coined by Linebaugh (2009), commoning initially referred to the rights of people to use common land. More recently, it has been used to refer to how people (as opposed to government agencies for example) make decisions that benefit their communities, focusing on what is 'common' in collective experience.

[227] These include the Black Humanists, Feminist Fightback, London Genderqueer Support Network, and The Sex Worker's Open University, all of which support people living and working in marginal conditions

[228] I was frequently reprimanded by interlocutors' families and even passers-by for lingering outside these places. Sometimes concerned strangers would ask me what I was looking for, as though I was in the wrong place.

logos, posters or other visual representations of their group. I would frequently find myself standing outside a dark building, scrabbling for a bell or doorknocker, without knowing whether or not it was the right place. To cite just one example, Bryan rang me before my first FLL event and suggested we meet outside the building. Feeling a little embarrassed, I said there was no need for him to greet me. However, on arrival I could not find the entrance. The building was extremely uninviting; it was dark, and the front door was broken, as though someone had tried to force their way in. There was old, dried vomit on the pavement, a sign stuck to a nearby lamppost warning against pickpockets and noisy cars sped impatiently past me on the narrow street. In the end I was very glad that Bryan did meet me that day. Meetings are often held in rooms without heating. The function room used by SAP has large damp patches on the walls and loose wires hanging from both ceiling and walls (see photograph below); the landlord once notoriously commented that he lets SAP use the room, "at [their] own personal risk and safety". Participants occasionally joke about the lack of proper lighting, yet most appear not to be affected by, or even notice, these conditions.

The discomfort I frequently experienced on arriving at these venues alerted me to the possibility that activists may consciously seek out inaccessible and unwelcoming spaces and that these spaces may therefore have some significance for them. For instance, many such sites have been carved out by and for, political dissidents and social outcasts. For example, over the years the Kingsley Hall, a popular activist venue in East London housed the Lister sisters, the Suffragettes and others seeking refuge, as well as several individuals and groups who were in hiding – including Mahatma Ghandi, Extinction Rebellion (XR) protestors and R.D. Laing's experimental therapeutic community in the 1970s.[229] These sites being so well concealed can be seen as a deliberate political act, one that ensures the anonymity and security of meeting participants.[230] However, as I shall explore, these spaces were also open to everybody and anyone.

After a year of being-in-places with various groups, I began to experience activist spaces in a way that contrasted strongly with my initial perception. It became clear to me that certain spaces are not simply the physical setting for social and political events but an

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[229] Laing's community aimed to create a therapeutic community that operated without restraints or psychotropic drugs. Nadia is a trustee of the Hall, and often talked of its energy and power. Mental-health activist conferences and healing events (such as gong baths and deaf yoga) are often held there.
[230] Particularly considering many of these centres hold therapy groups and meetings for sex workers, unionists and other groups that are anxious to protect their anonymity.

expression of activists' core values—or in other words, the site where their worlds are forged. This understanding arose from a mix of interlocutors' comments and the specific relational practices I observed whilst participating in activist events. In this way, my impression of the landscape of mental health activism changed from the unforgiving environment it had once appeared to be, to one characterised by acceptance, empathy and attunement. Having been 're-claimed' and tailor-made to meet the social and political ends of activist groups, the spaces used by activists hold powerful affective memories for group members. This understanding resonates closely with Cooper's (2004, 5) study of the transformation of medical spaces in Caracas, which concludes that through practices and acts of care, places gain "meaning as loci of safety, socializing, and inclusion". For example, I attended a keynote lecture at the Bethlehem mental hospital (also known as Bedlam) given in memory of an activist who helped found Mad Pride. During the break, Janet wandered around taking photos of art activists had hung on the walls.[231] She murmured, "Through our culture, it's how we speak about who and what we are…these spaces are what we make of them". Similarly, whilst hanging out with members of the 'Cool to Be' peer support group, the threatened closure of a local library was discussed. There was general agreement that the closure was unjust and would be devastating for the local community. One interlocutor exclaimed with outrage, "libraries and community centres are basically poor disabled people's social lives".

With so much invested in certain locations, it seemed important to establish what interlocutors felt was special or particular about activist spaces. During a Covid-19 pandemic lockdown in 2020, Will was confined to his bedroom in supported accommodation. I called him at Christmas via zoom. He explained with frustration that "survivor spaces need to be places where people can 'just meet' with flexibility, trust, freedom and no constraints", adding that he feels more at home in settings that emerge spontaneously, or 'just happen'. In drawing out what is distinctive about activist spaces Will differentiated between activist social norms and sociality and what he defined as 'normal', or every day, social life;

> I don't often hang around with normal people, so I'm not actually used to being so guarded about things... I don't really relate to people generally because they've

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[231] 'Survivors' are a particular branch of mental health activism, a specific way of defining oneself through survival of mental health services and/or of psychiatry, as explained in the introduction and glossary.

had such different experiences and have such different attitudes and things. Sometimes people seem quite serious or curious when I'm speaking to them and not relaxed. It's a front and you can't get past that. It's so unfree speaking and strange. I've never not been in an inner circle of people who haven't been autistic or mentally ill… they seem more normal- a normal bunch of people with normal sets of problems compared to me, like psychosis and depression. Some of us used to meet at the park outside our hospital. This space wasn't official, it just sort of happened…. People were coming and going all the time. Sometimes people would just tell me everything about their lives, I found it difficult and disconcerting and amazing and shocking. It was a natural thing to do- we could just talk, out of the ward. It is an emergent culture and maybe it's subversive cos there's normal culture which is cold and frosty. I see it fleetingly when I find myself talking to regulars, fleeting experiences of normality. The atmosphere is very strange- there are so many rules…. There is a culture of intolerance of just talking about anything. I'm not sure what you are allowed to talk about. I don't understand how people interact with each other outside these places and actually be happy. They say, "What the hell are you talking about," "What the fuck mate", there's just boundaries there and guardedness. But this is a counterculture; this could be the real culture if we were freer maybe. I can be very close with other people. It's a totally different dynamic. The point of it is, you can just be who you are, yourself, whatever, without the various expectations or norms getting in the way of that.

Quite a few activists expressed views very similar to Will's, often contrasting what they regard as safe activist spaces with other, unsafe, spaces. When a visitor at a FLL event asked members what a "safe space" was, one woman replied that it is a place where she knows she will not be judged. Another said that it was where she feels surrounded by "her culture" (meaning, mental health survivor culture); although she did not explain what she meant by survivor culture, much later she stated, "… these events are our day centres". I took this to imply that events, happenings and moments are more important to her than locations and buildings. Likewise, Nadia, who has been attending FLL meetings for twelve years, remarked; "Forget the therapy room. We need to be spending time with people, mingling and chatting".[232] When asked what, more specifically, appeals to her about FLL

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[232] As Nadia's quote highlights, some 'places' (e.g., the therapy room) are important to interlocutors because they invoke memories of locations where they suffered. Her statement typifies a kind of 'people over place' sentiment that is echoed among many activists whilst also pointing to what she considers to be more important—that is, being with people.

meetings, Nadia replied, "I need that space to articulate thoughts. Sometimes they don't come out as I want, or I say one thing one minute, then change my mind the next. I need people who don't hold me to account" She also commented that; "Just by getting together, we are saying that we're not OK about something… we're trying to grab small pieces of the power back". Lissa put it similarly, "generating safe spaces is not about having shared beliefs. It's about being able to have your *own* beliefs." Members also talked about mental health activist groups being 'life affirming'. These observations imply that activist spaces not only offer refuge for those who fear scrutiny, but also environments in which interlocutors feel they can experiment with their thoughts and express themselves freely without being interpreted, mediated or constrained by others. [233] In these examples, activists' physical and social spaces seem almost to be conflated, in that it is only through activists' relational practices that space acquires meaning. In the worlds built by activists, action seems to be less important than 'presence', or 'being-with' others. "Being with" in this context is about not trying to challenge people's health or illness narratives or expecting them to change or 'fix' themselves. Instead, it means maintaining a stance of 'openness' in which there is room for continuous experimentation. [234] Section two examines this process in greater detail, highlighting how activists' relational practices enable the forging of alternative therapeutic worlds.

Returning to the short vignette at the opening of this chapter, when the manager of the mental-health service-user café,[235] Dawn, acknowledged, 'between you, I think you've got what it takes', she was alluding to something quite important. For her—the professional wellbeing representative—neither the specific table nor the particular role was important; Bryan and I could undertake the function of wellbeing representative as well as the representative could. Dawn had met us before several times and was familiar with activists' ways of being. We tended to congregate at the café, sometimes with people we had just met, along with others we had invited. Sometimes we would bring friends and attract a small crowd. We would sit, talking, reading, eating and accompanying one

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[233] It is hard to articulate the powerful, embodied sense of 'letting your hair down' that is present in activists' spaces. The expression of strong emotions is common in these spaces. Ben once described it as "letting go of having to manage bodily habits and emotions all the time around others". Others talked of people feeling able to "go crazy" (also referred to as "going through madness and out the other side") in these spaces, the implication being that individuals are allowed to 'let go.'

[234] See also Chase, who argues for 'leaving space for irresolution and polyphony' in the unstable terrain of mental health in Nepal and other global mental health initiatives (2019; 263). Some interlocutors do not find the 'open stance' of meetings easy. Janet commented that allowing freedom of expression means that she is not always able to walk away from "horrible and disruptive people".

[235] Due to funding constraints and rent concerns following the Covid-19 pandemic, this pop-up café has been suspended and the staff made redundant.

another through the day, no matter who arrived. Dawn had admitted to me that she was 'very sympathetic' to mental-health activism, and sometimes felt that service-led initiatives missed the point. She inferred that, in contrast to the trained professional whose place we had occupied, Bryan and I had the capacity to help others, partly just by *being* there, and being 'us'; by being-together we created our own healing space built around mutuality, attunement, and acceptance; that open, negotiable space, undetermined by services, where different ways of knowing, approaching and understanding distress can meet.

Later that day, I asked Dawn about how she felt about other organisations and spaces in the capital city which were designed around the notion of 'wellbeing'. She responded that it was not the specific places or activities which were important; the most therapeutic thing for people was *each other* – (what she called 'peer support') – and not exercise classes, cakes or candles. But, she added, people *do* need places to go which enable them to be together *without* spending money, or time constraints.

4.3 Modes of organising [236]

"The most radical thing you can do is get together and have conversations. Feelings of connection are good. They are what drives hope really. However small." (Will, 2019)

This section examines the practices that underpin the organisation and content of activism, primarily, activist events and gatherings. I find that activists are deeply resistant to what are considered formal modes of organisation--membership regulations, meeting agendas and the like—having a preference for what some activists describe as 'structureless' relational practices. At first glance, these practices appear random. However, I suggest that, in fact, they reflect an important ethos of healing, one that centres both on accompanying, or being-with, others and on allowing anyone who chooses to participate to do so on their own terms and without judgment. The inclusiveness and tolerance of all kinds of behaviours is best understood by conceptualising activists' relational practices as a rejection of organisation---or even an intentional form of (non)organising. This analytic framing resonates with Krøijer's account of climate activists in Copenhagen.

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[236] Much of this section has formed part of the paper, Armstrong and Pratt-Boyden (2021) - the included extracts of which I was the sole author.

> The best way to describe the form of organization found among Left radical activists is probably with reference to Evans-Prichard's (1940) idea of ordered anarchy among the Nuer, who were organized in egalitarian segmentary groups … a system of relatively equal and small autonomous groups, which periodically come together to form larger communities (2020; 12).

Before commencing fieldwork, I had assumed that activists would convene meetings for a specific purpose and would seek a concrete outcome, such as a campaign plan, or agreement on an issue of mutual concern.[237] I had also imagined that there would be some predictable order to the process. These assumptions seemed valid in view of the political dimensions of many of their activities, and especially given the amount of time and money expended by some participants when travelling to and from activist events.[238] However, my assumptions turned out to be incorrect; in practice these gatherings appeared quite disorganised. Official leadership or facilitation is very rare and there are seldom any formal terms of engagement, most meetings being steered by whoever wants to speak at any point in the process.[239] Often, it is not even clear when sessions start; in the early phase of field work I would frequently sit waiting for some time before realising that there was to be no formal start. As a consequence of this permissiveness, the content of meetings is unpredictable and the process reactive, responding spontaneously to participants' personal stories, current events or news items. As Kieron indicated, there are "no ground rules… we're all just human beings". Similarly, Nadia remarked about FLL meetings that it was difficult to convince people who 'dip in' that the group 'did' much. With indignation, she pointed out that: "We've lasted 11 years!" noting that, "Just by getting together, we are saying that we're not OK about something… we're trying to grab small pieces of the power back". Some interlocutors talked about mental health activist groups being important simply because they exist; "It doesn't matter what we *do,* it's just *being* that counts".

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[237] This assumption is partly based on earlier fieldwork I undertook with mental health activists (2011-2012) at the Occupy London tent encampment. I found that political organisation was a key principle of the life and running of the camp

[238] For example, a participant at one meeting I attended had travelled all the way from Kent and another from Reading.

[239] Interlocutors rarely attend large-scale mainstream conferences, often because they are not invited. When they do attend, they seldom adhere to social conventions, speaking long past their allotted time, heckling or interrupting speakers they disagree with and refusing to follow a predefined script.

Despite the seeming disorder surrounding these gatherings, I came to appreciate that there is something systematic about the relational practices activists engage in during meetings; hence my conceptualising them as a form of (non)organising.[240] My field notes are replete with observations that bear this conception out. For example, in one case I noted that;

> The meeting had a strange, wandering quality to it. I didn't think Nadia or Liz [FLL members] had really agreed on what they were going to say or do. They seemed to want things to develop spontaneously, 'organically'. People talked haphazardly, interrupting each other, changing the topic of conversation without pausing or reflection (fieldnotes 2018).

My sense of frustration at the seemingly disorderly nature of these meeting is apparent from another extract;

> We begin an extended discussion about workfare, kicked off largely by Janet. Again, I am struck by the lack of structure to the discussion... People begin talking about whatever they feel like at the time, which means we listen a lot to Jan talking about depression; she isn't just 'talking' about it- she's *reliving* it… after a while listening to her solemnly, someone asks a question and then people are off… interrupting one another, sometimes calling things out in a tongue-in-cheek way. I am surprised that people seem not to notice how others *haven't* spoken, or don't try to give each other space. It sometimes feels like everybody has their own pre-prepared conversation…in their heads, which they can't wait to get out... It doesn't seem very thoughtful... often I feel a 'lack of connection' in such discussions (Field diary 2019).

The impression that meetings are intentionally (un)organised is reinforced by interlocutors' evident dislike of formal procedures. My queries around process would frequently provoke references to the oppressive forces of 'psychiatry', 'therapy' and

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[240] I often found myself wishing that meetings had more formalised structure, so that I could understand better what was going on and find out who the participants were.

'capitalism', these being systems and modes of behaviour that activists consciously reject. For example, Steve described himself as being 'anti-therapy', by which he meant "that all my activity with ex- mental patients takes place on a horizontal level". I sensed that, for some, the rejection of formalities may have to do with the potential for documentation to risk unwelcome exposure to inspection by outsiders, including being accountable in a way that might restrict expression.[241] In one RMH meeting a newcomer to the group asked why no one was taking minutes, pointing out that minutes enable people who cannot attend to remain informed and involved as well as to contribute remotely. The reply was that; "if we took minutes, everything we say would be scrutinised. It could get out of context and people would feel documented, like what they say would be analysed". Similarly, groups like FLL resist using any manifestos or descriptions of their group, preferring to post mad art and 'nonsense' depictions on their website. Also, it is rare for activist meetings to have an agenda; the only agenda for an FLL meeting that I saw was a note scribbled on the back of a scrap of paper in the form of announcements which read "two deaths, one memorial". Likewise, there are seldom any introductions at FLL meetings and participants are expected to introduce themselves; sometimes strangers wait for hours before deciding to explain who they are. FLL also shun all financial transactions, including refusing donations, the grounds being that they do not want to be held accountable to donors. Kieron explained why; "You then become subject to someone else's rules and agendas, like [National Service User Survivor Organisation]. You become a different organisation altogether, and it's no longer in your hands". Shauna agreed, arguing that it is precisely because they refuse donations, that FLL has been going for so long, since funding creates inequity and divisiveness.

The informality and spontaneity of activist gatherings is such that there are no constraints on who attends, why and when. Nor are there any expectations around participants' contributions during the events, or their conduct more generally. Frequent behavioural patterns during gatherings include walking about (sometimes called 'pacing'), talking without restriction and movements that are commonly interpreted as symptomatic of illness and therefore normally hidden from public view.[242] These latter

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[241] Activists' dislike of documentation (and particularly, being 'written about') is discussed in chapter 3.
[242] Some of these behaviours are common side-effects of psychotropic medications. For example, largactil (chlorpromazine hydrochloride) can induce 'pacing' – colloquially known as the 'largactil

include repeatedly getting up and down from chairs, moving about either very quickly or very slowly, dribbling, excessive scratching and involuntary eye movements. Interruptions are also common. On one occasion a man began playing the piano loudly, bringing the discussion to an end. To my surprise, participants did not stop him but rather listened contentedly to his frenzied performance. At another gathering, a man left the circle to climb onto the roof. We watched in tense silence as he walked around above us, his feet smacking dangerously on the thin glass of a skylight. I was not the only one breathing a sigh of relief when he climbed back down, though was struck that no one helped him to safety. Other examples were when Julie joined a meeting that was already forty-five minutes in and began shouting that "meds" were her sole Christmas present and that she had had to queue for an hour get them. She sat down and asked for a strong drink. The rest of the meeting was taken up with Julie talking and the rest of us plying her with drinks; in the process, she downed a whole bottle of wine. On a different occasion a man burst into the hall where we were meeting. He had a bottle of whiskey in his hand and appeared to be intoxicated; he was mumbling incoherently. We sat patiently, to see what he would do next. He spoke to us for a short while before leaving. After he had gone, Nadia lamented, "When people come to see us, we have no idea why they're here… they don't usually say, and for that reason, you have to welcome *everyone* … and after they're gone… you can't tell if you've made a difference to them or not".[243]

Similarly, a young girl who had recently been discharged from hospital (and heard about FLL from other inpatients) joined one gathering just to share her good news and eat a piece of cake. Another disrupted FLL's 13th birthday party. She took over an hour to recount her struggles with an abusive husband, who had locked her out of the house

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shuffle'—other effects include dribbling, slurred speech, or eyes involuntarily rolling into the back of the head. Many activists report being unable to express these symptoms in public due to the reactions they invoke in others. The stigma of not being able to control one's body is alienating to many and has been covered by (Bradley 2019) and others. Hiding physical symptoms of illness can change how people move about in spaces and interact with others, as documented in qualitative studies (e.g., Ridge et al. 2019).

[243] Some interlocutors expressed frustration at the lack of structure and direction to activist events. For example, Dan joked about how, at FLL, "there's no beginning or end", to which another participant retorted, "But is there even a middle?" Bryan explained that he finds the lack of 'structure' in meetings problematic and tried to circulate *The Tyranny of Structurelessness* (Freeman 1972) to the group. However, it was not well received. There are also frequent arguments—some of which are quite fierce— and some find the lack of provision for solving disputes frustrating, as Steve indicated, "when there's no structure, it can be difficult to resolve issues".

without a key and left her wandering the streets. She requested shelter from the cold and some spare change. Keiron gave her some fruit and a cup of tea, after which she left. Keiron's action reflects what appears to be an unspoken understanding that everyone is welcome to join these gatherings, however they behave, and without having to explain themselves.[244] Sometimes family members sit in on meetings. Nadia's brother joined one gathering. He was in acute distress and did not speak to or interact with anyone. Nadia explained that he just came 'to be around people'. The daughter of one of the SAP members attended another gathering. We had a brief conversation about how sparkly her water glass was. Struggling with the side effects of medication, she then sat staring in silence for two whole hours.[245]

Although I was initially perplexed by the lack of formal directive in activist gatherings, I came to appreciate that there are strong patterns in the way they are organised and conducted. Above all, structure and organisation are rejected in favour of simply accompanying, or being-with, others. This means allowing anyone who wishes to speak up about—or enact—their distress to do so in whichever manner they choose and without intervention or judgment. Conducting meetings without clear structures involves not having to make formal commitments to, or take, responsibility for oneself or for others. It is also a refusal to adhere to procedures of accountability. The open-minded tolerance, inclusiveness and freedom of expression that typifies activist events stands in stark contrast to interlocutors' experiences of formal mental-health treatments.   For interlocutors, the values embodied in activists' relational practices are a marker of an individual's moral worth, this being a more effective route to healing than medication and formal talk therapies.[246] With activist gatherings involving long, wandering, orations and participants keen to speak out, listening is another vital component of these practices will be discussed in the next section.

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[244] That said, perturbed by the request for money, Nadia said to the woman "this isn't the space for (that)".

[245] It was not always experienced as a positive thing to hold open, non-interventive meetings in which people could behave as they liked. Janet once commented that "in her normal life" if she ever came across someone who was being "disruptive and horrible" she would walk away from them and that "would be it". But in activist spaces, she commented "anyone can come" and upset people and you can't "nip it in the bud".

[246] Many studies of therapeutic groups understand them as arenas of self-governance. In his recent ethnography of voice-hearing groups for example, Noorani interprets the fact that people do not come to therapeutic groups if they are doing really badly or very well as a kind of self-regulation practice (2011; 94).

4.4 Listening

"It feels like there is so much that could still be learnt from survivor voices and experience in this mad world, yet still, no one is listening"
> *- Rai, conference on 'Social Power and Madness' (Cambridge University) (2021).*

"Thanks for being there and thanks for listening"
> *- Amir, an email to SAP Googlegroup (2019).*

The politics of speaking and listening

In this section I address one particularly important dimension of activists' relational practices: listening. I explore "how listening brings humans into being" (Lipari, 2014; 2) and suggest that it is central to activists' processes of healing. I reason that for activists listening is a vital constituent of collective and personal (inter)action and as such is imbued with therapeutic, social and cultural significance. I begin by outlining the politics of speaking and listening among activists. I frame their attention to listening as a response by people who, due to their diagnosis and treatment for mental illness, have been systematically silenced by clinicians and society alike. I show how activists' listening practices enable multiple, sometimes contradictory, 'voices' to be heard, and also suggest that when activists listen, they generally refrain from scrutiny, evaluation or intervention. In this way, listening can be seen as an embodied practice; a form of skilled attention (Grasseni 2012) and non-directive support, in which activists' personal narratives are legitimised and they become attuned to each another.

The act of listening is inevitably entangled with the act of speaking and cannot be understood outside the context of the wider mental health activist movement. There is a drive in the movement to ensure that survivor 'voices' are heard in both public and political discourse (c.f. Beresford and Wallcraft 1997). Listening also has historical and affective meaning among activists, as demonstrated in the above comment made by Rai during a mental-health conference. When activists talk about not been listened to, this encompasses many ways of feeling silenced, both literal, metaphorical and political. Giving voice is also referred to as 'speaking out', which in the context of activism consists of the narration of personal struggles in public settings (Crossley 2000; 1999; Crossley & Crossley, 1998).[247] In both ethnographic explorations of therapeutic practices (Steffen

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[247] One of the reasons given by interlocutors for speaking out which is less commonly found in the literature was to 'offload' – unburden oneself of their stories.

1997; Orsi 1996; Hunt 2000), and the sociological studies of mental health activism (Cresswell 2009; Crossley et al. 2001; Crossley 1998; 2005; 2006) speaking is awarded significant remedial value, the latter is also framing it as a response to the stigma attached to mental illness.[248] These literatures generally regard speaking as more powerful than other methods of communication, and as a consequence they generally neglect listening (c.f. Bell 1998; Gubrium and Holstein 1995; Weinberg 2005); while speaking is conceptualised as a form of active politics, listening is taken to be a passive state or even act of deference (Lipari 2001).[249] It is my contention that this conception negates the highly political, embodied and affective nature of activists' modes of listening.[250]

Is anyone listening?

With individual narratives driving so many activist events, much is required of the listener. Activists' listening practices are cultivated in different and particular ways—they are implicitly learnt over time, each meeting informing a person's 'training' in listening. A small but productive anthropology of silence (c.f. Warren 1993; Ross 2001; Gammeltoft 2016) demonstrates the importance of silence as an act of resistance. Norris-Green (2018) for example has documented how the style and quality of silence in Quaker meetings unsettles dominant cultural expectations around communication, breaking the hegemony of speech—as when individuals feel compelled to fill silence by talking. Crossley and other mental-health activism scholars (Crossley et al. 2001; Creswell 2005) argue that when activists 'speak out', the emphasis is not necessarily on what is being said, so much as how it is listened to, and that it is listened to *at all*. Listening involves time, energy and concentration—a significant ask of people who may lack these resources.[251] Listening demands persistent attention; it involves directing your attention to the storyteller in explicit and straightforward ways.[252] Grasseni's (2014; 2017) conceptualisation of how attention can be 'trained' is pertinent to understanding activists' listening practices. She highlights the different, learnt ways in which professional cow breeders 'look' at the animals to assess their functioning in terms of milking. 'Skilled vision', she explains, is the "capacity

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[248] For example, Crossley notes that speaking out is fundamental for building a sense of community and identity among mental health activist groups.

[249] Speaking is also often privileged as the most important mode of communication in research; researchers having emphasised narrative in mental health treatments

[250] At the time of writing, there have been recent talks about listening as a form or reparation, truth and reconciliation process (see Spandler and McKeown 2022).

[251] Eventually, listening became a specific line of enquiry.

[252] Having said this, activists also allow great flexibility; so, listening is not expected if it conflicts with one's own needs – i.e., if somebody is too agitated to listen, or needs to leave the room.

of looking in a certain way as a result of training", or what she also describes as a 'trained perception' (2007; 45), an informal way of understanding how to look that develops over time. Among breeders, vision is approached as "a proactive engagement with the world – a primarily social activity" (2011; 24). In a similar way, there are certain physical elements to listening—which can include ceasing all other activities, maintaining eye contact with the speaker, or tilting your head silently to invite further discussion. Activists listen through a kind of 'gesture of presence' - which Cubellis (2020, drawing from Bergson 2001) describes as "an embodied attunement (or sensibility) to the experiences of others" (15). Since activists' accounts can take many hours to relate and often have no obvious ending, listening also necessitates considerable patience. Moreover, activists' narratives regularly cover difficult topics, and absorbing the pain of others can have significant emotional impact; yet, at the same time, this does not seem to concern listeners. As Mosse (2020) argues, patients in mental-health settings are constantly pushed towards making sense of and communicating their experiences through narratives, particularly coherent ones.[253] However, the capacity to shape coherent narratives, or even to speak, seems less important to activists than is their ability to listen. In sum, listening is a responsibility of such importance that anyone who does not listen without good reason can expect censure. There are also ways of listening well.

The significance of 'listening well' became clear to me during the first months of fieldwork when a relationship with an interlocutor broke down because of my failure to take his experiences seriously. Steve and I were having a friendly exchange on messenger. Somehow, we started discussing a mutual friend who had recently confided in me that she was having a relationship with Steve. The woman was hoping that their affair would go somewhere. But Steve saw it differently. Complaining that she had been harassing him, he began to make serious accusations against her. He argued that she was sexually harassing him. "What she is doing is not OK." Cautiously, I began to question him about the nature of these messages and whether 'harassment' really was the correct interpretation of her behaviour. Steve replied with a long monologue; "If you don't appreciate the seriousness of this then I can't be friends with you. This is real. My mum has been really upset by this. My mental health has been affected. Sexual harassment is wrong, end of. I can't believe you stand by while people are sexually harassed." "Eventually, Steve unfriended me and

[253] An argument reinforced by scholars in different disciplines is that mental health professionals in particular look for coherence in narratives as a sign of sanity- they mistrust interlocutors when the narrative appears inconsistent (Mühlfried 2021).

blocked me on all social media.[254] I took Steve's response to my questioning as a reflection of my failure to listen unconditionally to his testimony. This interpretation is supported by Mike's explanation of what he perceives listening to entail,

> You don't have to *do* anything about people feeling shit, you just *listen*. When someone says, 'I'm freaking out because the TV is talking to me' or, 'I feel like the council are going to evict me', we just say 'that's really shit'. We don't say – but that's not true, that's not going to happen (Mike, 2020).

The common thread running through these (and other) examples is the desire to be listened to, heard, and accepted, without question or dispute. I once asked Will, whether he 'believed' that a patient had been raped by staff; frowning, his response was a follows; "I don't know, I'm not sure. But that wasn't really important anyway." What *was* important was that the patient had strong feelings and worries that were being ignored or dismissed by staff and that Will listened to him, unquestioningly. Activists seldom offer up opinions about other peoples' narratives, regardless of their accuracy, or credibility. Accepting someone's interpretation is perceived to be vital for giving them a sense of legitimacy and more fundamentally, to confirming their very identity. Many times, I encountered the trope that if one says something is the truth, then it is to *them* and therefore *must* be acknowledged as their reality. This approach contrasts with professional mental-health practice, in which the practitioners' role is not simply to build trust but also to probe, question, and challenge the patient's interpretation of events with the aim of enabling them to understand themselves and others better, and view things differently. Further, it is not just that listening has significance for activists but that they have particular listening norms; adhering to these norms is considered an important marker of respect and attuning to others. This is illustrated by the following vignette, which describes a FLL meeting:

> It is a cold evening in October. Participants are sitting in a haphazard circle in the unheated hall of [social centre]—apart from Lou, an older, disabled man in his seventies, who always sits close to the door so that he can leave quickly and open it for arrivals. Nadia starts the session in a roundabout manner by recounting her effort to keep herself strong, healthy and 'sane' without relying on anti-psychotic drugs. From participants' nods of recognition, I get the impression that they have

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[254] This is despite our friendship having lasted several months and my having visited him at home while he was unwell.

heard this narrative before, probably many times. Nadia describes how, a couple of years ago, she stopped taking her medication.[255] This was an abrupt move. Venturing out on a solo camping trip in a remote setting, she endured withdrawal symptoms by relying on meditation and a healthy diet, along with herbal remedies; it took two full weeks. Since then, she has not had any other major episodes of distress nor experienced further withdrawal symptoms. A short while into Nadia's narrative, Eric asks her why she tried to 'replace' the medication with other remedies. This leads to a disagreement about whether you should 'compensate' your body when coming off anti-psychotics. Nadia argues that if "you take something away from your body, you must replace it, whether herbs, Chinese medicines or exercise".[256] Eric does not agree. He points out that Andy has also stopped taking his anti-psychotic medication and claims that Andy's main 'compensation' for doing so is no longer having any 'dodgy chemicals' in his system. In Eric's view, Andy is happy to have rid himself of all substances. Nadia takes offence, reasoning that herbs are 'not the same as substances'. The quarrel ensues until, fixing Eric with a stare, Nadia snaps, "You sound like you are *not* talking to someone who's ever come off antipsychotics". Her words hold a dangerous warning tone—--as if to say, if you continue, you will cross a line. Nadia has played the 'trump' card; Eric does not have direct experience of coming off anti-psychotics (or indeed, of mental distress) so his perspective is taken as less valid than hers.[257]

There is a short silence, some participants watching the pair and others looking distractedly elsewhere. Suddenly, Clare pipes up; "I've been diagnosed, and misdiagnosed with many things, but they've settled with schizophrenia". People become alert, glazed looks lifting, sit up in their seats and settle into listening to her. Her words fill the small community hall where we are meeting. Something strikes me; it is not so much her account that I find interesting, but how her intervention changes the atmosphere in the room. At first, I think that participants

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[255] This can be sometimes referred to by activists as a 'medication strike'
[256] Nadia's hearing aid is playing up and she speaks with mounting frustration.
[257] This is part of wider efforts to platform mental health evaders/survivors over anyone else. Activist circles are considered sacred by some as places where people with 'lived experience' of mental distress should take up most of the 'space' (figuratively speaking). Carers are often welcomed, but this is controversial for some people. Eric in particular has often been accused of "not being a service-user" and he is regularly reminded of this fact.

are simply glad that the fraught exchange between Nadia and Eric has been brought to a close. But it is as if listening has only truly begun with Clare's narrative.

Clare speaks for a long time about how her "schizophrenia" commenced in 1983, either when fly larvae laid eggs under her skin or a worm laid eggs in her ear. She is certain that this happened during night while she was asleep because she woke up the next morning feeling different. She gives us a detailed account of how the larvae may have entered her body and hatched, as well as the side effects they have caused, including which nerves they have damaged. She seems keen to share all the information she can about her condition, as though doing so gives her some comfort. Clare does not normally attract much attention from others and seldom speaks openly like this in gatherings. Yet participants are listening intently; Andy for example stares straight at her and Nadia cocks her head to one side in concentration. Clare tells us that, over time, GPs have stopped listening to her. Once, after complaining about the pain in her ears and head, she was X-rayed. She could see a 'squiggly line' on the X-ray and showed it to the doctor. [258] Giving her a copy of the image, he pointed out that there was no such line. She tells us that this was in fact an entirely different X-ray—it was not even of her head—claiming that the doctor had hidden the original one. We listen quietly and carefully, nodding occasionally in apparent agreement with her. I think about how the FLL flyer advertising the aims of the group describes it is a space for survivors to come, talk and share things, "even if seemingly irrelevant". It is hard to follow parts of Clare's story, or to understand what she wants us to get out of it, yet everyone is listening intently.

Clare goes on to say that "the majority of my mental health problems are because I couldn't speak when I needed to." She adds, "sometimes a little bit of voice helps". Someone in the audience agrees with her, murmuring that, indeed, "it makes us feel more human". Twice Clare tells us that she was trained as a nurse, holds two degrees, and has published frequently in well-known medical journals; when trying to clarify a complicated connection between fly larvae and neurotransmitters she explains, "I'm a scientist". Some people have puzzled expressions on their faces.[259] She quips, "they [medical professionals] know we're not thick and we've got degrees". She looks around at us carefully as she suggests that perhaps mental

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[258] Clare knew the squiggly line was a worm.
[259] She uses so much medical terminology that I do not understand what she is saying or manage to write it down.

health professionals *stop* listening because they *know* (her) truth, but *do not want to,* or *cannot* acknowledge it. The room falls silent as Clare finishes speaking; there are a couple of sympathetic tuts, and some mumble disapprovingly about the behaviour of medical professionals. I wait for someone to challenge her account, although soon realise that no-one is going to.

The meeting revealed a lot about activists' approaches to listening. The argument between Nadia and Eric, especially Eric's inability to assert his viewpoint, is typical of activists' interactions. As someone who has neither been diagnosed as mentally ill, nor taken antipsychotic drugs, his perspective enjoys less legitimacy in activist circles than does Nadia's. The contrast between Nadia blocking Eric's opinion and the way in which Clare's story engaged her audience also speaks much about who 'deserves' to be listened to. Striking in this latter exchange is that the audience listened unconditionally. Initially I found it hard to interpret the silence that followed Clare's intervention.[260] Yet this kind of exchange, in which audiences remain silent following the delivery of a powerful personal narrative, was just one among countless such examples I encountered during fieldwork. After the meeting had finished, I went to a café with Eric and Andy and tried to find out more about activists listening practices from them. We briefly discussed Clare's account. Although Eric did not explicitly say he found the story farfetched, he rolled his eyes and uttered in a sceptical tone, "she still goes on about her fly theory".[261] Meanwhile, Andy stared straight ahead with clenched teeth, remaining silent. Knowing Andy well (he is usually very outspoken) and aware that as a former psychiatric patient he has been disquieted in the past when his own accounts have been doubted, I interpreted his silence as reflecting his reluctance to dispute other people's truths. I heard Clare recount her story many times, at diverse activist meetings and with different groups. Despite its details changing at each telling, still, audiences consistently refused to critique her account, or indeed engage with it in any explicit way.[262] I found this quite surprising, particularly since Clare did not always operate the same acceptance of others. She is quite a controversial figure who often picks fights and can be pedantic and particular about information.

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[260] I wondered how Clare felt after telling her story. Did it matter to her whether she was believed or how her story was understood? Was it enough that *she* believes, and that people (seemed to) listen? I also wondered if she has ever shared this account in full with mental health professionals and if so, whether they simply stopped listening to her.

[261] I was struck by Eric's dry, jokey tone, because laughing at someone's truth, especially behind their backs, is usually disapproved of. In fact, this was the only time during fieldwork that anyone behaved like this. I interpreted it as a response to her controversial character.

[262] Sometimes the animals changed (i.e., flies instead of worms) and sometimes the symptoms did.

From these numerous meetings, I take activists' listening practices to embody a particular understanding of reality; one that it is fluid, contextual and unique to speaker and listener (see also Introduction, section 2.3). From the speaker's perspective, listening is a validating process in that it demonstrates a willingness to hear out, as well as a deep respect for, their narrative—however troubling it may be. I argue there are also unintended consequences of facilitating listening; telling a story multiple times allows speakers to experiment with how their ideas and theories sound out loud, with different audiences and in different contexts, and also, how it feels to be listened to without challenge, which may have reinforcing effects on the speaker. The way activists listen is quite distinctive because it requires the listener to suspend their own reality—leaving a speaker unchallenged, whether or not their account is plausible-- and accept another's truths. Delivering these accounts as a stream-of-consciousness rather than a linear narrative, without a start or end point, nor a rationale as to why they are being spoken, also makes possible—and more likely—a neutral response from the audience. Embedded in these practices of listening is a fundamental stance of non-intervention and non-analysis, in which contradictions, different stories, and alternative endings, are left to play out. Interlocutors often pause or leave long silences during and after a monologue. By listening to and valuing these narratives without trying to deny or adjust them, activists are able to 'guard and hold space' for one another and thereby foster healing as acceptance of one another's truths, much as Johnson (2020) describes in her ethnography. The next section takes this argument further by suggesting that guarding and holding space for others through intentional acts of listening is perceived by activists to be a collective responsibility. In this way, all of those participating in activist gatherings become involved in healing.

Listening as attunement

Few activists are able to access training in therapeutic skills.[263] However, some have had the opportunity to attend peer support workshops, co-counselling sessions and similar events. These events often feature capacity building in listening techniques. The specific approach to the teaching of listening and listening skills are highly appreciated by activists,

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[263] It requires time and money to participate in these courses as well as a certain level of emotional and mental energy which training sessions means that this kind of formal learning is available to few people. Attendees tended to be those who sought informal facilitator or leadership roles in activist events and particularly those with financial or social means.

such that their deployment by interlocutors in activist gatherings is regarded as a 'gift' to the wider activist community. Drawing mainly on one such event, a 'radical peer support' workshop in Northeast London, this section demonstrates that learning listening techniques is taken to be an important form of self-work among some activists, or what some workshop facilitators term, 'attunement'. As it was explained to me, attunement describes a way of responding, orienting oneself toward, and accustoming oneself to others. What is important about activists' approach to attunement is that it is taken to be a collective responsibility, as can be seen from the exchanges that took place at the workshop.

The workshop attracted a diverse group of participants, including mental health professionals, third sector workers, (self-defined) 'service-users', and carers. We sat in a large circle and waited for the chief protagonist, Silas—a lead figure in alternative mental health support movement in the USA.[264] Silas had been touring Europe over the summer, presenting his experiences of radical peer support to diverse audiences. He stood to one side for some time and then walked forward and greeted the room, speaking slowly and deliberately in a relaxed manner. As he spoke, his eyes moved continuously around the room, watching each and everyone in the audience keenly. Silas has a history of mental distress and has been sectioned several times. However, he explained that he grew up in an environment in which, rather than resorting to medical services, people supported each other and as an adult has always lived in communes where mutual aid is vital.[265] He made clear that much of his wisdom comes from the care he has received from others when he has been 'out of it'.

Silas began his talk by arguing that, "If you do peer support right, you will be a magnet to all sorts of intense, brilliant, crazy people. But you do need basic ground rules". [266] In his view, holding a space in which it is "OK for some folks to be on psychiatric drugs", is central to effective peer support. He went on to admit, "I take them every day….and they seem to

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[264] Silas co-founded a USA-based radical mental health mutual aid group which emphasises 'different' ways of interacting with one another, and 'breaking down habitual ways of interacting' (for more info see anon, 2020).

[265] Mutual aid is a term used widely in American activist circles, and more recently in the UK, post-pandemic, and refers to groups set up to exchange resources and services. An example is skill-sharing. Jupp defines mutual aid as a "hybrid between informal neighbourly help and formalised charity" (Jupp 2022; 108).

[266] I am surprised as he says this, because not once in activist spaces have I heard anyone mention 'rules' in an explicit way.

work for me… but it's also ok for others not to like them."[267] Silas argued that acceptance and valuing difference are also crucial, "You have to be able to hold space for complexity." He paused and went on, "But before I begin this workshop properly, I need everyone in this room to engage in 'owl listening'". He explained what he meant by 'owl listening',

> 'Owl listening' is when everybody in the room takes responsibility for everybody else, so that the onus is not on one particular individual. So, even though I may be the one speaking right now, and you are actively listening to me, you also need to have an awareness of what's going on in the whole room. You need to keep 'an eye out' on everyone and pay attention to others. So…when someone is speaking, you can engage with them by listening to them, but you also can be scanning around the room – making sure no-one's freaking out, for example, or people aren't falling asleep, or waiting to speak. It's about reading the energy in the room. The speaker needs to be doing this also, to make sure that what they're saying is actually being heard, is wanted, and being received. If people look kinda tired, well then, maybe it's time for a break, or to move on. People require different levels of listening, so it's good also to be aware of that. And there are those who are listening, but may need to fidget or stare into space, but they might still be taking it all in.

Silas sought responses from the audience, asking participants to reflect on what they feel about using their personal experiences of distress to support others and to put any questions they may have to him. One man spoke up, explaining that he had travelled all the way from Spain by bus to hear Silas talk. The man was extremely nervous and looked down at his feet as he spoke. Stuttering, he apologised that he was unable to finish his sentences. Silas's reaction to this man revealed more about his approach to listening, showing how it can be interpreted as a form of attunement. Replying to the man that, 'it was no trouble', Silas walked over and kneeled right in front of him, resting his hands on the man's knees. Looking directly up at the man, Silas listened intently as he continued speaking.[268] When the man finished talking, Silas stood up and, rather than replying directly to him, addressed the room.

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[267] This is arguably one of the most controversial issues among activists and others who reject biomedical approaches to mental distress.

[268] This gesture could have been intrusive but somehow – it was gentle.

We listen like allies…. We don't judge or invalidate other people's experiences. When it's our turn to speak we ask others for advice and feedback, or just have people listen without responding. We encourage quieter people to speak by asking louder ones to step back…. 'If you have come here to help me, you're wasting your time, but if you are here because your liberation is bound up with mine, then let us work together.'[269]

For Silas, owl listening is a form of mutual engagement—a way of attuning to others in an embodied way. He demonstrated this not just by listening carefully to individuals as they spoke, but also simultaneously attending to the group; he tracked everyone in the circle with his eyes. In scanning the room continuously, he was able to check that they were all engaged and faring well. At the same time, by calling on others to engage in owl listening, Silas was highlighting how all of those present had a role in attuning to and healing others. This takes the onus away from the individual whilst also exemplifying the ability to engage with the individual and the collective at one and the same time. Zigon (2021) refers to this dynamic as being able to 'attune' to others whilst maintaining one's individual trajectory.

Silas's listening methodology echoes the approach used by many in the mental health activist movement, in which collective responsibility for and a commitment to hearing others out, prevails. Moreover, there is marked physicality about Silas's approach to listening and his body language conveyed a message of attunement that was as strong, if not stronger, than his words. As he spoke, he turned to ensure that he faced his audience and when the Spanish man spoke, used his body to show that he was listening by kneeling at the man's feet and gazing into his face. He did not respond verbally to the man, since it was more about the way he listened to him. The physicality of activists' listening practices also embodies a strong emotional element. This was emphasised by Alice when speaking at a mental health conference. She commented that, "If you're here as an ally, please listen with an open heart, not your head" (Alice, 2019). In Alice's conceptualisation, there is a way of listening with your body as opposed to your mind – meaning that you are invited to listen through feelings of mutuality and empathy, acknowledging the speakers' truths rather than by interpreting their narrative according to your own understanding or perspective. Personal truths are deeply respected and rarely challenged; by listening, activists also hold open

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[269] This quote is used by activists (also across the 'Mad in America' movement) but was originally used by Lilla Watson, a Murri (indigenous Australian) activist at a UN 1985 Decade for Women conference in Nairobi, building on a motto coined by a Queensland Aboriginal Rights group.

space for experimentation. Thus, for activists, attunement is not just a physical act but also one that is extremely demanding emotionally. The idea of embodied attunement is discussed further in chapter 5, which shows what this practice entails when it is extended outside activist meetings to interpersonal interactions and integrated into everyday life. The chapter argues that by displaying embodied attunement individuals are able to confirm to themselves and others that they are engaged, outward-looking persons, this being an essential expression of their personhood and community as well as a vital condition for their healing.

In this section, I paid attention to the different techniques of listening and the philosophies that connected them such as 'attunement' and 'space holding'. I demonstrated that despite listening being considered an 'inactive' form of political action and resistance, it is in fact dynamic. Listening and being together, although commonly undervalued forms of politics, are actually constitutive of worldbuilding.

4.5 Chapter conclusion

In this chapter I showed how activists make their own healing spaces across London, which contrast markedly with the highly controlled, predictable and routine-driven environments of conventional therapeutic locations. Therapeutic space-making involves constructing worlds which are entirely 'other' from conventional biomedical settings such as the clinic, or hospital, operating within economic constraints. For interlocutors, worlds are constructed partly in response to what they know they do not want, based on their memories and experiences of being in institutional settings run by the NHS and DWP. Biomedical spaces are often designed with the intention of relieving or resolving a person's distress, psychiatric and psychotherapeutic treatments emphasising solutions and narrative coherence. Conversely, for activists healing spaces are where they claim to feel 'normal', usually by being-with other people who also experience mental distress. These are spaces where activists are able to talk about stigmatised and taboo topics and embody movements and behaviours that they cannot express outside activist contexts. A key therapeutic aspect of activist space-making is the creation of environments in which they can express themselves freely without fear of judgement.

In section one, I demonstrated the specific ways in which biomedical settings carry a strong negative resonance for activists. I argued that traditional clinical settings are not organised in a way that allows patients to 'be or act relationally'. I described the kinds of locations activists meet across the city; in run down, disused places such as parks, community centres and hospital gardens. I reasoned that while some of these locations might appear hostile, unsafe and anonymous, often they are carefully chosen in order to be accessible to anyone, or because of their historical connections with other activist or dissident groups. I found that certain activist spaces are endowed with significance and meaning, but that for the most part, activists meet in locations that are not *inherently* significant for them. In section two I discussed what is important in activist space-making. I showed how activists are deeply resistant to formal modes of organisation, having a preference for relational practices of, what some activists described as, 'structurelessness'. The lack of structure means that activists' behaviour in meetings can be highly unpredictable. Most actions are permissible in activist spaces and self-expression is highly valued, including certain behaviours that might be classified as dangerous or pathologized elsewhere. I used Zigon's (2019) concept of maintaining 'openness' to describe this approach in which intentions become intrinsic to the form of meeting*.*

In section three I developed the notion of openness further by outlining activists' practices of listening, which I likened to Grasseni's (2010) 'skilled modes of attention'. Listening can be seen as an embodied practice in which activists' personal narratives are legitimised and activists attune to one another. The act of listening signal—and is entangled with—values around participation, mutuality and inclusivity. I showed that when activists listen, they generally refrain from scrutiny, or intervention. Although it is impossible to tell whether listeners make judgement about what they hear, they listen with certain embodied qualities, without comment. This creates an environment in which because listening is *anticipated* it allows people to speak freely and feel accepted by individuals and groups. Listening opens up new possibilities for activists to facilitate greater personhood, in the sense that it cultivates respect towards their singularity and diversity as individuals.

By resisting formal organisation and through practices of being-with one another and embodied listening, activists create spaces of sanctuary, meaning and belonging, throughout London. Creating 'open', 'structureless' spaces enable different perspectives to coexist and offers a form of relationality that contrasts strongly with that found by

activists in biomedical spaces. In activist settings, 'reality' is never defined – multiple positionalities are presented, tolerated and listened to. This could be interpreted as a kind of pluralisation of truth, in that there is no one, accepted single or consensual version of events or happenings. Further, rejecting formal rules for behaviour and avoiding definitions of distress means that activists can move in and through spaces as they wish, allowing them to find their own ways to heal. Without enforced structures, interlocutors can speak without restraint; there are few recognisable hierarchies to dictate who can speak, the open-ended character of meetings enabling spontaneity. Thus, interactions in activist gatherings hold more potential for responding to individuals' needs in the moment. Healing can be achieved by journeying through different strategies or processes and allowing things to happen along the way, in turn opening up greater possibilities for being 'otherwise'. I have shown that healing spaces are not tied to particular locales and do not rely on set agendas but are enacted through relational practices; spaces *become* important because *being-with* enables people to form relationships across geographic boundaries and allows intermittent relations between strangers. In other words, healing is carried through relational practices across diverse locations and networks, such that 'any' place can become therapeutic.
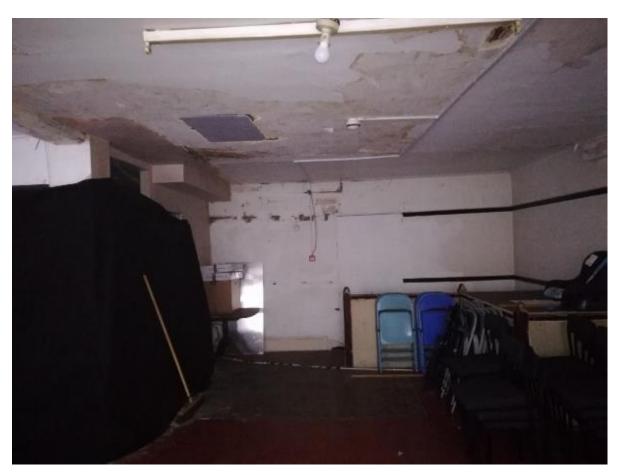
Figure 3 The meeting place of Stand Against Psychiatry

Figure 4 The meeting place of Friends of London's Loons

Figure 5 Reading at 'Picnics are a Health Outcome'

Figure 6 Meeting place for regular get-togethers with in-patients (local hospital on the left)

Chapter 5: 'Other ways to Care': Enacting Mutuality

5.1 Chapter introduction

"All we have is togetherness" – Janet (2019)

In the introduction to this thesis, I outlined why the concept of mutuality, as deployed in the kinship literatures, is a useful way of framing activists' relational practices. In this chapter, I develop the argument further by analysing interlocutors' actions, discourse and relationships. The chapter heading, 'Other ways to Care', is taken from the title of an activist conference in which participants called for new approaches to mental distress that centre on relationships of affect, which they perceive to be a vital facet of care and one that is lacking in Treatment as Usual. Unable and/or unwilling to accept the tenets of TAU, activists pursue a system of mental healthcare that acknowledges both the social and the political dimensions of mental distress; this is about integrating '*other* ways to care' within their daily lives. I explore the meanings activists give to such an approach, as well as the ways in and extent to which it is applied in everyday practice. In using the framework of mutuality, I draw on Schlecker and Fleischer's definition, which is that mutuality entails a form of "existential sharing […] a longing for conviviality" (2013; 12). Mutuality is very different from being inherently 'tied' together through consanguinity or biological origin; it is much closer to Carsten's (2000) conceptualisation of relatedness, although I argue that it is broader. The principles embedded in mutuality strengthen social and political forms among activists. As Antze and Lambek note "People are related to one another when they remember how and why they have a kinship obligation" (1996; 40). Forged particularly during crises, activists' relations are both dynamic and deliberate, and form their primary network of support.

In the context of mental-health activism, mutuality can be seen as a counter to the powerlessness, isolation and individualism which interlocutors describe as typifying their experiences of mental healthcare. Mutuality captures activists' efforts to subvert the caregiver/receiver dichotomy which characterises western mental healthcare and discourse. It conveys the dynamic processes underpinning activists' caring practices; through mutuality, activists prefigure relationships that are built around relatedness,

support and belonging. This is not to imply that mutuality is invariably consensual and cooperative. Activists' relational practices entail many complexities and contradictions and much precariousness, this inferring that while there is often an *intention or desire for* mutuality, this is not fully realised in practice.[270] Thus, relationships of mutuality are forged collaboratively, or co-constituted, and must therefore be negotiated—a process that sometimes ends in connections between people breaking down. [271]

In the first section of the chapter, I summarise my preliminary observations around activists' relational practices, whilst also presenting the case for using the term 'mutuality'. In section two I examine how mutuality plays out in activists' daily lives, as well as underlining its chief characteristics. I argue that despite highly dispersed social networks and often unstable relationships, activists are very invested in attuning to each other. This is evidenced by the many ways in which interlocutors appear to identify with, are accepting of and reach out with compassion to advise and assist fellow activists, as much as by embodied practices such as shifting one's focus to the other and engaging with another's perspective. Mutuality also captures activists' efforts to subvert the caregiver/receiver dichotomy, a dynamic that characterises western mental healthcare and discourse. Thus, reciprocal caregiving and care-receiving are crucial to activist mutuality; ideally, as far as they are concerned, these roles should be balanced.[272] Activists' orientation toward equivalence in mutual support explains why I do not use the term 'care' to describe what goes on 'in between' (Zigon 2021) interlocutors. Care is a loaded term that is rejected by many mental-health activists (and indeed, other disability movements).[273] Finally, I argue that generally the trust and acceptance embedded in activist mutuality is extended unconditionally, including to complete strangers. However, I go on to show, in section three, that relationships of mutuality can also exact a high emotional cost, insofar as they may become burdensome or involve contestation and conflict. I suggest that activists' experiences of the suffering of others can become tied up with, and even indistinguishable from, their own pain. Nevertheless, I conclude that conflict and wounding are not simply

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[270] Mutuality, like reciprocity, can be delayed and is not instantaneous and transactional (see introduction). It is difficult to 'measure' or to track among activists, but can often seem 'out of balance', hence why I describe it as 'not fully realised'.

[271] I challenge the 'positive' perceptions of care and relationships in social movements (such as the concept of 'solidarity') which assumes that such relations are built around a "warm, fuzzy glow rather than a cold shiver" (Carsten 2013: 246).

[272] Although I do not refer specifically to gender dynamics in this chapter, a similar philosophy and ideal of 'balance' and the equal distribution of support applied across the genders. It was my observation that although both men, women and non-binary persons played equal roles in supporting one another – the majority of administrative and organisational matters fell to and were led by women.

[273] C.F. (Thomas 2007).

sources of pain, since they also generate a sense of safety, security and connection and are thus symbolic and constitutive of the kind of mutuality activists enact.

Having argued for the significance of mutuality in activists' relational practices, I now outline the evidence for this by exploring the process of mutuality as revealed in everyday practice. Each of the sub-sections highlights one of the key features of mutuality.

5.2 Conceptualising activists' relational practices

During one of my first FLL meetings, I see Nadia holding her phone. A note on it reads,

> *X 3 funerals*
> *1 birth*

The simplicity of her note stayed with me in the months to come and came to form part of my understanding of relatedness among activists, which can be seen in the sharing of information and everyday life events. Here, I discuss the significant and everyday elements which constitute activist mutuality, such as– keeping one another informed of others' whereabouts, updating one another on news relevant to the community, and attending significant events such as funerals and christenings together.

I begin this section by summarising what I initially learned from my enquiry into activists' relational practices and explain how I came to conceptualise these in terms of mutuality. Among other early observations, I noted the tenuous nature of interlocutors' familial ties. Following years of mental distress, combined often with extreme financial insecurity and bouts of challenging treatment, sectioning and hospitalisation, interlocutors' relationships with family and friends can be strained and estrangements are common. Bryan (fifty) for example, does not take medication (having rejected a diagnosis and prescription) and manages his distress by leading a nomadic life; living on the streets and being able to leave places when he needs. He is supported in this endeavour by activist networks and other friends. His mother disapproves of his choices and has forbidden him to return home unless he concedes to biomedical treatment and moves into fixed accommodation. He has been couch-surfing for near to thirty years and cannot imagine ever changing, so is waiting for his mother to die so that he can gain access to and rekindle a relationship with

his father. Similarly, Andy's wife and son live overseas, and he has very little contact with his family. His brother lives in the UK but Andy chooses not to see him out of fear that his brother will try to get him sectioned.[274] Nor is Alexa, a middle-aged Cypriot who works as a freelance survivor researcher, in touch with her family. However, she is not reconciled to this situation and described living with her best friend and housemate as 'faking' a normal life.

It soon became apparent that the fragility of interlocutors' familial ties stands in stark contrast to their relationships with fellow activists. Although these relationships often appeared strained and unstable, interlocutors regularly went to extraordinary lengths to aid other activists, frequently doing so at significant personal cost emotionally, financially and in terms of time. This generosity of spirit was commonly extended to complete strangers. Most of the effort was focused on helping each other live independently and avoid unwanted intrusion by family members or medical professionals. Thus, activists provide information and guidance on what to do during a mental-health crisis, how to plan for encounters with mental health and other professionals—particularly how to avoid sectioning and hospitalisation—and how to obtain benefits. They also offer tangible support such as food and accommodation, as well as going to great lengths to offer encouragement and emotional attention.[275] Such acts of kindness are all the more striking when one considers the precarious lives most activists lead, and the limited resources they access.[276] Then again, it is conceivable that activists' relational practices are directly linked to the precarity of their existence, a possibility that is implicit in the remark made by one interlocutor (quoted at the beginning of this chapter), "all we have is togetherness". This sentiment resonated throughout activist networks, some interlocutors going so far as to say that togetherness is what sustains them, being essential to their health and wellbeing, their sense of independence and belonging. As I will go on to show, activists need for each other to lead independent lives, otherwise the pain of others' suffering can have serious consequences and become unbearable.

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[274] Whilst I helped edit Andy's memoir, he became animated and pleased. "If I had a loving family," he said, "this is the kind of thing they would be doing now". I felt uncomfortable, trying to make light of the task, joking that not everybody's family would have the patience. He repeated that a family member would be doing this kind of thing, instead of me.

[275] For example, FLL members carry cards listing one another's contact details for use in an emergency.

[276] Just one example is when Greg spent his entire months' travel budget to visit Will during a short period in hospital.

The enactment of mutuality among activists is similar to other informal economies of care or resources which arise between people of distant or dispersed connection during times of crisis (see e.g., Borstein and Redfeld 2011; Jupp 2012; Al-Mohammad and Peluso 2012; Mittermaier 2014).[277] Observing the importance given to togetherness and providing support, I focussed my enquiry on what these phenomena might signify for activists. Mutuality appears to operate as a diffuse, unspoken philosophy. I was curious to know why so much is invested in supporting one another, what interlocutors' motives might be and what impact it has on those who are supported and supporter. In particular, given the emphasis of activists' discussions on speaking freely and spontaneously about what are often extremely painful feelings and experiences, I was concerned that those listening might experience "triggering"— or, in other words, a strong emotional reaction that builds on previous adverse experiences and causes difficult responses.[278] I suspected that triggering might be one of the reasons why interlocutors regularly drop out of or take breaks from activism.[279]

However, researching these topics turned out to be far from straightforward. My attempts to learn more about activists' relational practices through direct questioning were repeatedly thwarted. When I asked about what I referred to as 'caring' roles and responsibilities (as I framed it), and whether 'caregivers' experience 'burn out', interlocutors expressed clear discomfort, by raising their eyebrows, scoffing or laughing awkwardly.[280] I tried framing my questions differently to no avail. For example, Nadia, Julie, Janet and Lissa all perform key roles in maintaining the FLL, SAP and RMH networks and supporting individual participants. They organise attendance at events, arrange taxis, give people lifts, check on regular attendees, call members, regularly

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[277] In particular, Jupp discusses the politics of 'getting by' in difficult circumstances, building networks of support as well as making demands of those in power (2019, 3033).

[278] Triggering is a concept I initially used when entering the field to try and understand how interlocutors might be affected by exposure to the experiences of other people's suffering. The term is widely deployed in activist circles globally, particularly in liberal Western contexts. It also features in the work of anthropologists such as Raschig (2016) and Johnson (2019), who focus particularly on the temporal aspects of 'triggering', for example, the feeling of 'going backwards'; also framed in terms of 'temporal tripwires' (Povinelli 2011,13). However, because of its close connections with psychopathology, the term is not used and broadly disliked by interlocutors.

[279] Now I understand this fluid movement between and in and out of groups to reflect 'disclosive freedom', as describe in the following chapter.

[280] I asked many interlocutors about 'burn-out', which has specific connotations in Euromerican activist circles and refers to the 'using up' of one's personal and emotional energy for the sake of a cause or collective effort. It signals significant emotional investment in a particular issue and usually those affected are expected to need a period of respite or recovery before returning to activism with renewed energy. Like triggering, this proved to be an unpopular term among activists because it has implications for the burden of care born by individuals, as discussed in section 3 of this chapter.

provide snacks, send out emails, invite guest speakers, inform members of deaths and funerals, and liaise with venues. Nevertheless, they refused to concede to my suggestion that their contributions were greater than those made by others, particularly in the ways they looked after others. My questions about whether they saw themselves as a key part of these networks were met with evasive responses such as: "I never speak on behalf of anyone"; "I just do the emails"; "I rarely speak in the meetings anyway"; and "everyone puts in equally". Nor would they acknowledge the wider place of care in the networks. When I made a joke one day about Julie having cooked and served a full meal to a group of demonstrators, she replied firmly, "Everyone does what they can". After a while, from these kinds of remarks, I came to understand that even though 'caring' is not interpreted or articulated as such, it is an integral, though taken for granted, feature of activists' relational practices. The term 'care' in particular is besmirched as something that professionals do. In other words, for activists, 'care' is a word used to veil power imbalances, hierarchies, hidden intentions and secret agendas. As Heineman reminds us, 'informal' care (i.e., care that takes place outside of designated contexts) is often not recognised as caregiving, even by those providing the care (Heineman 2013; 69), particularly in settings where care is not regarded as desirable in those terms. Thus, the paradox of activists' relational practices became apparent; despite being central to the fabric of sociality, discourse around support (and 'care' in particular) remain implicit and unspoken. In saying this, I am not arguing that overt 'caring'/'cared-for' relationships do not exist among activists, but rather that they are not straightforwardly transactional—as I hope to show in the following sections of this chapter.

Possibly because of prior experiences of formal services, activists also communicate a fair amount of uneasiness about caring acts, especially about being in receipt of unidirectional care, a circumstance that many find quite troubling. In trying to comprehend and conceptualise these kinds of complexities in activists' relational practices and identify what about them is distinctive, I settled on the concept of mutuality. The premise is that activists have an affinity with each other that is over and above familial and other ties, this affinity somehow setting them apart from all other individuals and buttressing their relationships with fellow activists. Such affinity arises from a shared array experience of suffering, grievance and uncertainty.[281] I argue this because practically all of the

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[281] I use the notion of 'shared experience' cautiously; activists themselves resist the homogenisation of their voices and experiences, but this is to recognise some similarities of experience without undermining heterogeneity.

discussions and activities that I participated in centred, in one way or another, on interlocutors' experiences of mental distress, frightening and unjust encounters with service providers, discrimination and stigma and/or struggles to find contentment and forge a happier life. Indeed, it soon became apparent that sharing and embracing suffering and working together to find ways of alleviating is a core motive underpinning activist networks.

Mutuality encompasses the ways in which distress (and healing) are intersubjective experiences. Schlecker's mutuality draws from Sahlin's 'mutuality of being', (2011a; 2011b) which is a specific attempt to reconceptualise kinship, emphasising relationships between people who are 'intrinsic to one another's existence' (2011a; 2). Mutuality of being emphasises the procedural and transformative experiences of daily life (Stone 2004), for example, Sahlins points to how affective and material experiences create affinity, for example, through the sharing of food, memories and suffering (Sahlins 2011b: 5-11). Mutuality helps us to understand how individuals enact their relationships with others, how individual subjects relate to the "broader imaginaries of personhood and politics that circulate within a given place at a given time" (Moore 2011; 13). For example, 'Cool to Be' peer support members meet each week and take turns to talk about the challenges they have faced during the week. The challenges faced were significant; a child's suicide, terminal illness, domestic abuse within an arranged marriage, the murder of a family member, combined with the constant underlying presence of intrusive DWP surveillance and benefits sanctions. Interlocutors having undergone such experiences and struggled long with a multitude of emotional and practical difficulties, often exacerbated by systemic service failures and iatrogenesis, appear to have reached a level of mutual understanding that they do not find in their relationships with people outside activist networks. To give just one example of this, Greg explained that, because suicide is "more normal" and attempts are common in activist circles, he is more intimately connected to RMH members than he is to his mother or ex-wife. He feels he can more easily "understand where [RMH members] are coming from" and know or imagine what their experiences feel like. Sometimes, Greg reports, all it takes is a look, and he knows that another activist is feeling what he is feeling. In other words, by being unwell and/or experiencing an injustice or tragedy of one kind or another, interlocutors become attuned both to themselves and to others through responses and reactions.

Having argued for the significance of mutuality in activists' relational practices, I now outline the evidence for this by exploring the process of mutuality as revealed in everyday practice. Each of the sub-sections highlight one of the key features of mutuality.

5.3 The workings of mutuality

The critical place of attunement

Here, I reason that attunement is a fundamental feature of mutuality. Attunement is the purposeful orientation toward and (entanglement with) others. Zigon describes it as "being able to attune to, and consider, the disparity and difference of complex sociality without eradicating difference" (2021, seminar). Attunement is a phenomenological concept (as outlined in chapter 2) which I use to highlight how strangers or socially differentiated individuals "emerge from their own situatedness to become oriented to the situatedness of others." (Raschig 2017; 159). My argument is that activists' relational practices are notable for the degree to which individuals identify with, are accepting of and respond with compassion to their peers—a process that is both extremely intimate and intuitive and yet applies across highly dispersed networks and irregular relationships. This is not to suggest that attunement is an automatic state. Far from it, the workings of mutuality involve continuous negotiation, sensitivity to the feelings, emotions and individual needs of fellow activists, as well as an acceptance of behaviour that can be both highly unpredictable and potentially alarming to others. I illustrate this process of negotiation whereby people move toward each other (or 'attune' to each other) – by presenting two examples, each of which involved an activist who, at the time, was experiencing significant distress. In both cases, fellow activists put considerable effort into easing their disquiet and offering comfort, seemingly doing so instinctively, yet also purposefully. These examples are notable for the intentional use of body language—gestures, glances, and the like—and not just the careful choice of words, to convey understanding and empathy. This process is very similar to that described by Kleinman, including "the way we look at someone, and receive or return their gaze; the way we connect (or fail to do so); the quality of our voice, our very presence" (Kleinman 2015; 240). But there was no script, and the exchanges were mutually constituted through experimentation and adapting to the mood of peers, much as Mol's (2010) concept of 'tinkering' or changing what seems best in the moment. Thus,

activists adapt their behaviour as well as the environments they are into support someone in distress.

A clear example of 'tinkering' involved Zola, a friend of Austin's, previously unknown to other activists. Zola, a young woman in her twenties, was struggling to come to terms with a recent bipolar-disorder diagnosis and had left her house only three times in over eight months. Even though she was unable to participate regularly in activist events in person or online, due to her distress, there seemed to be an unspoken understanding that she would be supported by the community. Having recently been added to the Fight the Power WhatsApp group, network members began sharing videos with her critiquing medical diagnoses and links to readings on label theory.[282] Some also posted supportive statements, such as "We got you". Eventually, Austin suggested that we arrange for Zola to meet up with some like-minded people who would be able to offer her more substantial interaction. We had not met Zola before, but Zee, a careful, methodical woman in her mid-twenties, Will, and I volunteered for this role.[283] I was struck by the careful preparation that went into setting up this encounter; throughout its planning and realisation, Will and Zee displayed extraordinary understanding and patience and made a great effort to accommodate Zola's needs, ensuring that she did not have to think about anything beyond immediate practical considerations. Recognising the importance of putting her at her ease, Austin checked with Zola and her partner what her requirements were, and a long discussion ensued about where best to meet Zola. We started looking for a site that was near Zola's home, one that would not involve journeying long on a crowded tube or changing trains.[284] Nor was the meeting to be held anywhere 'distracting', noisy, busy or cold, and it had to be somewhere that Zola could get away from quickly. Fight the Power researched tube lines to establish which were the quietest, had a station near Zola's home and would get her quickly to a location that met her criteria. In consultation with Zola, we agreed on a secluded spot in Regent's Park.[285] Situated off the public footpath, behind a fence and surrounded by trees, it was hidden from public view. We pinned the location via WhatsApp and gave Zola instructions on how to get there. Throughout her journey, Austin

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[282] Developed by sociologists such as Becker (1963) Mead (1939) and Goffman (1963), label theory posits that actors are identified and categorised as deviant if they deviate too much from the social norm (i.e., the mentally ill, immigrants, homeless people etc). Many scholars as well as activists have used label theory to critique the concepts of mental illness (c.f. Pilgrim and Rogers 1999; Markowitz 2014).

[283] Will and Zee agreed to the arrangement without hesitation, despite the detailed planning, time commitment and cost involved in arranging and participating in this meeting.

[284] It could not be at her house, because one of the main purposes of the encounter was to get her used to going outside again

[285] The cost of the journey to Regent's Park was the equivalent of Will's weekly food allowance.

supported her via texts, encouraging her to keep going when at one point her resolve weakened and she thought to turn back. We shopped and cooked food for the picnic, and in order to create a calm and welcoming atmosphere, arrived early and spread a picnic blanket on the ground. Concerned that Zola might find conversation with strangers difficult, we provided colouring pencils and books for her to use as a distraction.

Zola arrived an hour late. We sat together colouring, eating and engaging in light, though purposeful, conversation. Focused at all times on supporting Zola and increasing her sense of comfort, the discussion involved countless intersubjective exchanges and small, complementary acts.[286] It also entailed a good deal of patience, cooperation and flexibility, as well as social emotional and physical 'copresence' (Drotbohm 2015; 109).[287] We fetched drinks, and listened to, reassured and praised Zola, brushing aside several offensive comments, and steering the conversation away from emotive topics. We encouraged her to take care of herself, for example by getting more fresh air and joining a discussion and support group for women diagnosed with bipolar disorder. After an hour, Zola explained that she felt too overwhelmed to remain any longer and thanking us, stood up to leave. We accompanied her to the tube station, ensured that she caught the correct train, and texted her repeatedly until she reached home. This incident of coming together showed how acutely aware interlocutors were of Zola's distress and the lengths they were prepared to go to in order to serve her needs and give her comfort and advice.

The significance of attunement in activists' relational practices is also revealed in an exchange that Will, Alexa and I had with Steve—this incident bringing to the fore the way in which all of those involved benefit from these interactions in a way that is mutually reinforcing. Normally a regular and highly engaged participant in activist events, Steve had begun to miss meetings. Eventually he messaged Fight the Power members that he was "really not well".[288] Will decided we should pay him a visit to find out what was the matter. Alexa was already living with Steve.[289] Unlike the picnic with Zola, this encounter was entirely spontaneous, even so, comforting and encouraging Steve still involved an intense

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[286] The incident was not a one-off; there were many other moments when Zola benefitted from mutual support. A few weeks after the picnic, Zola became acutely distressed and lost her way in the centre of London. A group of people 'tracked' her location through social media and joined her with the aim of calming her down and preventing her from being hospitalised.

[287] Sahlins also uses the term copresence in his discussion of 'mutuality of being' to refer to the 'transpersonal unities of bodies, feelings and experience' (2011a; 11).

[288] This was an unusual statement for Steve, who typically described his suffering as a source of strength and inspiration, sometimes calling his distress a "dangerous gift".

[289] Alexa had been evicted from her house and was temporarily lodging with Steve.

effort. Getting to Steve's house involved a three-hour train journey; Will joked dryly about the cost of the tickets, although was careful not to imply that he regretted making the trip. When we arrived, Steve seemed reluctant to let us in, opening the door only slightly. Usually smart and clean-shaven, Steve's beard was long, his eyes were red and small, the collar of his dressing gown lined with a thick coating of dandruff.

Steve led us into the sitting room, walking past piles of abandoned takeaway boxes and cold plates of chips. Steve had been watching television, which was paused on a gory scene depicting a wounded topless woman in a hospital gown. 'Nice thing to watch when you're ill?' Will questioned.[290] Exclaiming, "I'm not well", Steve collapsed onto the sofa with a sigh, covering himself with a large blanket. Will, Alexa and I spent most of the day sat in the corner of the sitting room, and turning to look at him, listened intently as he talked. Initially, Steve seemed quite uncomfortable and was reluctant to let us speak so the conversation was quite stilted. Steve was keen to show us some video clips of things he had achieved, as though trying to prove something. He asked if we would like to listen to an audio recording of him being sectioned, which he had managed to record on his phone. He explained that he was finding it difficult to think and worried that he might forget what he wanted to say; his thoughts were unclear and difficult to order, and any interruption caused him to become more disorientated. Nonetheless, despite Steve's resistance, Alexa and Will persisted patiently in their attempts to establish common ground with Steve, drawing on their own experiences in their efforts to help him convey his feelings. Will interjected, "If you don't mind me asking, are your thoughts, like…*racing*?" "No", replied Steve, "I just *can't think*". "Is it like a fog?" Alexa queried. When Steve muttered something incoherent in response Alexa gave a small nod of recognition. Steve looked distressed; his brow furrowed. Eventually, he became annoyed and banged his fist on the table. Alexa responded, "But why do you have to *think* right now? Why not just sit here, watch telly and eat your food?" Steve contemplated this question in silence. At this point I wondered whether we had managed to get a better understanding of Steve's experience and were helping him, or merely increasing his confusion.

In time, Alexa's gaze became softer and Will's gestures gentler, constantly adjusting to Steve's increasing agitation. Steve and Will moved on to discuss activism, something

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[290] I reflected on this observation throughout the day as we proceeded to watch a film about a clash between a racist and police, a fierce debate in Hyde Park about mental illness, and when Steve asked us to pick our favourite 'fight' on YouTube.

which seemed to make Steve happy. During their conversation, they both became animated. Will was excited and told Steve he felt as though someone finally understood him and his relationship with activism. At first, Steve smiled, but then he became agitated and asked, "Do I talk too much? I want constructive criticism." While awaiting our reply, he looked nervously at the floor, as though seeking our approval. Smiling, Alexa said, "Instead of criticism… why don't we go around and say what we like about one another?" Will then communicated his opinion that we were "at the very least, reasonably intelligent", at which we all laughed. Trying to come up with an appropriate response, Alexa became muddled and seemed to lose her confidence. Smiling, Steve encouraged her to continue speaking, reassuring her that she was making sense. Then, addressing Steve, Will argued that he did not need to make 'grand gestures and gesticulations' to convince people; that he should believe in the content of what he is saying. Will's remark appeared to break-through to Steve, who smiled, and observed, "this is peer support right here" and finally began to look more relaxed.

Later that evening, to get Steve out of the house, we decided to buy some pasta and tinned tomatoes from the local shop. Steve rose from the sofa and stretched, but then, saying it was too difficult, promptly sat down again. Commenting that he had made a good effort, Alexa asked whether he might like to try again to get up, and when he did so, Will congratulated him. We spent the rest of the evening keeping a watchful eye on Steve, consoling him when he fell silent or became despondent, asking him questions and encouraging him to recount his memories. As we were about to leave, Steve looked us in the eyes and explained that letting us into his home had made him feel very vulnerable, adding, "Don't tell anyone I'm ill at the moment, I can't show any weakness. If you aren't confident, it gets you nowhere, and you will just end up waiting for things to happen for you and to you." Steve texted us later that evening to thank us for being 'so awesome'.

Reflecting on the exchange, I realised that even though the visit had centred on Steve, there were clear moments of shared understanding, recognition and acknowledgment throughout and that we had all somehow benefitted from these interactions. Indeed, after we left Will and Alexa expressed how much they had appreciated and gained from the encounter. Will talked excitedly on the way home about how relieved he felt to see how Steve's thoughts also sometimes disoriented him. Thus, I understood from this experience that attunement is not simply a matter of altruism, as it also nurtures the attuner. Even though some activists may *appear to be* giving support, their support for others is bi-

directional which sustains *both* self and other.[291] This is not to imply that supporting roles are bilateral transactions, since "the social system depends (more or less) on everyone providing (something) at some stage" (Widlok 2017; 23), the social obligation to repay being subsumed into wider networks. The way activists enact mutuality is through several one-way transfers going in different directions – in a larger circulation of exchange.[292] The philosophy of support is directed at 'activists' more generally, rather than individuals. In the following sections, I will expand on the notion that the 'self/other' distinction is further eroded by activists' experiences resonating strongly with one another.

The importance of balance

The dynamics of activist mutuality are complex and the give and take of support are finely balanced. Sometimes the responsibility of giving falls disproportionately on particular individuals; this can be burdensome and may increase anxiety, as shown in section three. But often the greater concern with maintaining a balance is to avoid reproducing the power asymmetry that so many activists have experienced as service-users. Thus, activists would frequently express apprehension about recipients of care (in any context- family or professional for example) being controlled by and/or dependent on caregivers. As a consequence, unlike professional relations of care, in which carer and cared-for are discrete, fixed roles, such boundaries tend to be blurred or even absent in activists' interactions. Interlocutors often undertake both roles concurrently, shifting imperceptibly from one to the other; in so doing, they ensure that giving and taking are reciprocal acts. Getting the balance right involves close attunement to others as well as intuition, as shown in the previous section. Steve's engagement in the exchange on the day we visited him was on terms that were rather different from the rest of us. Normally a prominent and confident member of activist networks, I had in the past heard him say that being 'sick' gives him social power, meaning and a reason to fight. But this was not the message he conveyed to us that day. When we arrived at his flat, he was hesitant to let us in. He was not able to control his thoughts and was therefore unwilling to let us speak. He also seemed reluctant to admit to being unwell and in need of care and requested that we keep his ill-health secret. It is possible that he was concerned about being stigmatised. However, Steve's discomfort

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[291] Criticised as a neoliberal construct, the self / other dualism is not particularly popular among activists, who express a preference for considering their healing process and wellbeing as fundamentally interconnected with other persons and society.
[292] As mentioned in the introduction.

seemed more likely to reflect a resistance to being perceived as vulnerable and dependent, especially if being in this state meant he was unable to reciprocate our care and attention. Whatever his motivation, Steve relaxed visibly during the course of the visit as Alexa and Will skilfully navigated the conversation in a more constructive direction and he too was able to offer up insight, encouragement and support to the rest of us. There was no particular turning point, but Steve became much calmer and accepting once he understood that the process Will and Alexa had initiated was truly reciprocal. The day with Steve also demonstrated the importance of staying-with a person, being 'alongside' them in their distress and tolerating their pain and bad moods.

The importance of balance and moderation in sustaining mutuality is possibly the reason why some interlocutors downplay the value of 'giving' care, i.e., to avoid inhabiting particular carer/receiver roles. Many are careful to talk about receiving support as 'leaning in' or 'walking alongside' others, rather than leaning 'on', or being supported *by* others. At the same time, the lack of recognition for those giving support can result in individuals being thought to give 'too much', as in the case of Eric. A retired schoolteacher with a pension, Eric takes pride in his expertise in legal matters and is very well informed about mental-health legislation. He devotes a great deal of time to supporting mental health service-users and activists, regularly advocating for patients under section, attending the Tuesday meet-ups, housing activists who need accommodation and providing various individuals with a meal at Christmas time.[293] He has successfully fought a number of legal cases on activists' behalf and has acted as Andy's official advocate (listed as his 'next of kin') for some time.[294] Observing that he seems to be 'on call' day and night, I asked Eric how he copes. With an awkward smile, he replied by questioning what I meant. I explained that he seemed very busy and wondered whether he ever tired of supporting people or felt the need for a break. He replied, "The way I keep going is the need for the right things to happen to the right people… to prevent people getting lied to, or taken advantage of by service providers, benefits schemes, or anything like that." In time, I realised that Eric did

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[293] A café at a London O2 centre is known to be open to all mental health service-users and activists on Tuesdays. When a well-liked mental health service-user died suddenly and unexpectedly, friends began meeting there to grieve together. The intention (as explained by Bryan) is to create a kind of casual 'drop-in' centre. The arrangement is very informal. Some come with specific queries or problems, such as paying bills, claiming benefits, or medication concerns, and others come to socialise. There are no notifications about upcoming meetings; attendance relies on finding out by word of mouth and participants simply turn up. On a couple of occasions Jack, one of the original initiators of these encounters, and/or I remained alone for the entire afternoon.

[294] One example being when Eric successfully took a mental-health trust to court for failing to inform him, despite his being listed as Andy's next of kin, of a change in Andy's treatment. Advocates are officially recognised on mental health wards.

not see himself as someone in need of assistance or support; in fact, he was careful to explain to me that he had never experienced (in his own words) mental 'illness'.

Interlocutors give Eric credit for and rely on his legal expertise. However, given that he positions himself firmly as a care*giver*, his constant presence in activist circles is quite unusual and sometimes controversial. Eric does not disclose personal information and generally keeps to himself—conduct that is not well received in activist spaces where personal stories are shared freely. Instead of being heralded as an ally, Eric is subject to gossip, rumour and suspicion. The concerns surrounding Eric are reminiscent of those elicited by mental health professionals, as indicated in chapter 4.[295] Activists frequently commented (to his face and behind his back) that Eric is '*not* a survivor, yet *hangs out* in survivor spaces.' Some said they were tired of hearing his 'endless legal rhetoric', and others accused him of having a simplistic understanding of the world. More seriously, there were a number of unfortunate rumours circulating about Eric– including that he is a paedophile and visits wards in order to, 'get into young girls' pants'. A number of activists raised a particular concern about Eric's relationship with Eva's son, Rob. At one meeting Clare accused Eric of being too close to Rob and told him that Eva did not like him 'meddling' with her son on the ward without her permission.[296] The ambiguous relationship Eric has with many activists and their suspicion of him is indicative of a widespread resistance in activist circles to caring roles that are too clearly demarcated or self-designated, particularly in the case of the 'caregiver'. Such unidirectional caring relationships are considered socially undesirable by activists, and potentially polluting in the sense that they disrupt culturally defined boundaries (Douglas 1966).

The kindness of strangers

One of the most distinctive ways in which activists' manifest mutuality is through the degree of trust and acceptance they show when reaching out to and assisting others. These acts of kindness are generally extended unconditionally, particularly during pressing times, irrespective of personal circumstances, resources, or the conduct of those on the receiving end. For example, activists regularly provide their peers with

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[295] Particularly the concerns around sexual violence and rape.

[296] Eric got to know Rob through Scouts, when Rob was age 11. Finding out that Rob (in his twenties) was sleeping rough in London, Eric helped Rob voluntarily section himself. However, Rob absconded from hospital, was found and then forcibly sectioned. Whilst in hospital, Rob asked for Eric to visit him in place of his mother, Eva, and stayed with him at weekends. This caused tension between Eric and Eva as well as with some activists, who found Eric's approach too conventional--especially the assistance he gave Eric in sectioning himself.

accommodation and food, sometimes allowing them to remain indefinitely; such generosity is surprising considering that rents in London are exceptionally high and interlocutors' incomes, typically very low. Moreover, these acts are frequently directed at strangers, thereby conforming to a tacit model of sharing in which individuals may or may not be known or connected to one another.[297] Widlok interprets this practice in the context of generalised reciprocity as enabling communities to protect themselves against resource variability and individual limitations (2017; 190). The following vignette, involving Aspen, illustrates this ethos. A former psychiatric patient, Aspen is in his eighties and lives in a basement flat in a small, north-London townhouse, which he bought with savings from work. Aspen's home provides a refuge for activists seeking shelter from the authorities and/or mental health regimes, many of whom he has not met before.

Late one evening, while drinking tea at the O2 drop-in centre, Bryan and Eric decided that we should visit Aspen. This was a spontaneous decision, and the visit was unannounced. It was dark, and after walking for some time we arrived at Aspen's home. Picking his way carefully past bikes to the front door, Bryan knocked loudly. However, there was no reply. Inside, music was blaring out loudly. He knocked again, calling Aspen's name. Since Aspen was not expecting us, I asked if we should have rung in advance, or at least visited during daytime. Bryan raised his eyebrows and pulled a face, as if to say, 'you don't understand' and continued knocking. After some ten minutes there was still no answer and Bryan became frustrated. "He's almost always in; I don't think he'd be out at this time of night. In the past he might have, but not anymore…" He continued knocking and I started to feel embarrassed, wondering whether we were being ignored intentionally. However, just then, the door opened, and a young man (Tomasz) let us in. Tomasz did not seem at all surprised by our impromptu visit, and wordlessly led us down a dark, narrow corridor packed from floor to ceiling with old books to what appeared to be the living room.

Aspen was sitting in the middle of the dark room, next to a small electric heater. To his right there was a tiny kitchen where Tomasz made us all tea and to his left, an array of Buddhist relics festooned with offerings. The room was draped in thick, soot-covered

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[297] I recognise that the term 'stranger' can mean different things. In this thesis, stranger refers to completely unknown persons, although there were of course varying degrees of 'felt' strangerhood. For example, if a person was clearly a Survivor, there was often assumed to be greater levels of intimacy and connection between (See Koch and Miles 2020 and Jupp 2022 for a discussion of how strangers can be 'invited' through imagined and assumed intimacy).

spiders' webs, and the dusty floor was littered with shredded newspaper and bits of chewed cardboard—the remains of numerous vermin infestations. Aspen explained that, as a Buddhist, it is against his philosophy to harm animals, so that the room had remained untouched throughout the thirty-five years he had lived in the house. There was a bed in the room constructed out of books and covered with tea towels and fraying sacks. Aspen clarified that he often has guests, some of whom stay for a long time, one having just moved into sheltered accommodation after more than thirteen years in the house. After we left, Bryan explained that he occasionally stays in Aspen's garden, in a tent, confiding that, "You have to be pretty desperate to stay there…some people who stay are bad people. Some are good, but mostly they just need somewhere to go, and have had bad experiences". He added that rats run freely throughout the house and noted the risk of contracting wiles disease from their urine. Yet, it was evident that, however dirty, the flat is always full of people. It is warm, and there is a constant supply of tea. There are plenty of beds made up for use and in the living room the books are stacked in such a way as to provide extra walls and rooms, presumably to afford guests some privacy.

We sat on camping chairs surrounding Aspen. Bryan asked Aspen to tell us about his experiences of mental-health activism and Aspen related several episodes from his long life. Disclosing that he had been sectioned 32 times, he had lost count of how many injections he had been given in the buttocks. Laughing, he recalled how one nurse had injected him 'right here' (pointing to his upper-left thigh) "right through my dirty jeans". He explained that he used to pace up and down outside the entrance of the Royal Institute of Psychiatry dressed in his Oxford University gown (he was a lecturer), shouting about the poor treatment he had received there; occasionally he would stand in the reception area with a large papier-mâché depot syringe in his hand. Eventually, he was banned from the institution. Aspen went on to relate how he had housed numerous illegal immigrants, mental patients (ex and current) and homeless people, many of whom were complete strangers to him. He had sheltered George, who sought refuge with Aspen, having been sectioned, subsequently escaped from his chaperone whilst on leave from the hospital. One afternoon, a contingent of twenty riot police arrived at the house searching for George, his records having indicated that he can be violent. The police forced an entry by breaking the front door down; Aspen described how he was sitting in his chair quietly drinking a cup of tea when a large police officer suddenly appeared in the doorway. Pulling a face, as though realising that it was a mistake to bring such a large group of policemen, the officer took Aspen gently by the shoulders, laid him face-down on the floor, and

handcuffed him. But Aspen was not prepared to go easily, so he poured cold water over the man and on his way out of the house, spat at one of the police vans.[298]

Aspen operates the refuge on the premise that fellow activists are inherently trustworthy and incapable of deceit. His guests are all given house keys so that they can come and go as they please. When I asked him why he so generously opens his home up in this way, he grinned and responded; "we are free here, it is no place for authorities…They are barred". There are no phones or computers in the house. However, I noticed a thick wad of bank notes stuffed in one of Aspen's pockets, some of which had fallen to the floor. Later, Bryan told me that Aspen had been burgled three times and voiced his suspicion that some of Aspen's guests had abused his trust by stealing from him. "Aspen believes that no mental health service-user can do harm" Bryan remarked despairingly. We remained at Aspen's house until late, when Bryan proposed that we leave. Aspen suggested that Bryan pitch his tent in the garden. Declining politely, Bryan asked if Aspen would agree to my returning to interview him another day. Aspen nodded and, smiling, handed me a front-door key. When I hesitated, asking him if he was sure that I could have the key, Aspen seemed highly amused and did not bother to dignify my question with a response. "Be seeing you" he called as we left.

Several aspects of this visit were notable. First, I was surprised that Bryan and Eric—both of whom are normally exceptionally formal and polite—thought it appropriate to make an impromptu visit, with a stranger in tow, to an 80-year-old man's home, especially late in the evening. Then there was the dilapidated state of Aspen's house, reflecting an adherence to Buddhist philosophy that was so strict as to ignore the potential adverse consequences. Most important, though, was the trust and compassion Aspen showed towards others and his tendency to put strangers' needs before his own. Bryan stated that he believes some of Aspen's visitors to be 'bad' people, yet Aspen seemed entirely unconcerned about the risks of running an open house. I was particularly struck by his willingness to hide an escapee hospital patient, the more so given that he had barred all 'authorities' from his home. Aspen's house was transformed into an intimate, welcoming site in which subjects and space are formed through "peoplehood" (Huang 2020) – a desire to unite against a common 'enemy'. Aspen's case highlights how mutuality among activists extends beyond emotional and practical support since it is also a profoundly

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[298] The police neither repaired nor replaced the door, which is now reinforced with thick wooden planks. Tomasz is helping Aspen repair and paint it.

political act to intentionally extend the offer of community to any person (a topic that I explore in greater detail in Chapter 6).

5.4 The wounds of mutuality

It would be misleading to imply that activists' relationships are wholly trouble free. During fieldwork I witnessed numerous arguments, some of which were fierce and lasted many months, if not years. Several interlocutors became disaffected from and dropped out of activist networks (often returning but sometimes not). But, above all, it became apparent that sustaining relationships of mutuality can be costly emotionally, physically and in other ways, and some activists found they were giving too much of themselves; as Al-Mohammad and Peluso explain, in situations of crisis, over time, "lines of care and concern emerge, are fostered and also frayed" (2012; 42). The greatest challenges to mutuality arose from activists' interactions with the mental-health and social welfare systems, which sometimes heightened interlocutors' mental distress. Thus, the core argument of this section is that relationships of mutuality are fashioned as much by struggle as they are by consensus and harmony. The example cited illustrates the emotional and affective fallout from enacting mutuality. One of the most important notions underpinning mutuality is the sense that activists should, or indeed must, do all they can to prevent others from being sectioned and forcibly hospitalised. This was the primary motive behind the intensive search that took place when at one point Andy had gone missing. That keeping fellow activists out of hospital is awarded such a high priority also reflects the deep suffering associated with compulsory internment and treatment. Yet providing this kind of assistance can be extremely challenging since it entails significant effort as well as provoking painful memories of activists' own experiences of hospital treatment. The events that unfolded following Andy's disappearance illustrate this argument well.

I had noticed that Andy was becoming increasingly agitated in SAP meetings and when I met with him to edit his memoir. I also observed that when we met up informally in cafes, he had begun to talk very quickly, changing topics abruptly and sometimes talking over me with a glazed look in his eyes, all of which was very different from his usual considered manner. I shared my concern for Andy with a couple of SAP and FLL members. One responded in a rather non-committal manner, "Yes, I've noticed his energy is different too.

We'll keep an eye on him". Others appeared to dismiss my worry.[299] Eventually, a seemingly mundane conversation during a SAP meeting between Andy and Lyndsey turned into a furious row. They shouted at each other for a long time. Andy accused Lyndsey of being racist towards Scotsmen, and Andy finally left, accusing us of failing to stand up for him during the argument. Following his departure, there were comments from members about how unreasonable Andy had been and how ungrateful he was.[300] Later that day, Andy emailed us all to say that, after ten years as a member of SAP, he was 'resigning' and would not be returning. He berated participants again for not standing up for him, complaining that this demonstrated a willingness to ignore the poor treatment of others. His email attracted a flurry of replies, some expressing regret and sympathy for Andy, and others, anger that he had created disharmony in the group. Janet emailed him the following message;

> Andy. My only intention is to offer some advice. I think the most important thing at the moment is to calm down. Your main aim should be to avoid hospitalisation. Shouting in public and writing lots of letters is going to draw attention to yourself. This is not going to end up well for you or indeed for the [clinical trial].[301] Your well-being is the most important consideration at the moment. Think logically. Hope all goes well. (Email, 2018)

Janet's main concern was that Andy might draw attention to himself, thereby risking enforced hospitalisation, which in her view was likely to cause him far more suffering than his poor mental health.

Over the following weeks, FLL and SAP members kept in touch with Andy through texts and emails. However, we soon realised that he had stopped replying. His absence was mentioned at meetings, and other activist networks were also notified. FLL and SAP participants began actively searching for him, telephoning all of London's psychiatric

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[299] This response aligned with the implicit norms of conduct during network meetings. Activists seldom intervene regardless of participants' conduct. Rather, meetings are spaces for people to show up in whatever state they are in and act how they please (see chapter 4). Although Andy would speak about all kinds of things unrelated to the topic being discussed, sometimes interrupting others, he was allowed to continue.

[300] Andy had failed to thank them for visiting him in hospital and at home, eaten all the crisps without himself contributing food, and they also found him too pedantic and argumentative.

[301] Andy was enrolled in a controversial clinical trial run by a radical critical psychiatrist who seeks to establish how patients can be weaned off antipsychotics for good. Activists shared that participating in the trial is very prestigious and some envied Andy for being involved. The trial is not referenced here for confidentiality and anonymity reasons.

wards multiple times, filing a missing person's report, and attempting to reach him by email, social media and calling him repeatedly on various devices. To aid the search, Nora shared Andy's photo with a friend who works at her local police station and Janet asked a friend employed at a nearby mental-health hospital to discreetly check if he was there. Meanwhile, Bryan looked for Andy in all the churches, drop-ins and day centres near Andy's home and went to the O2 drop-in meetings for some weeks in the hope of finding him there. But these efforts were futile.[302] A search was also underway for Eric, who had disappeared around the same time. [303] All the while, speculation about Andy's whereabouts circulated throughout the SAP and FLL networks, as in the example texts and emails given below;

> I last saw Andy standing on London Bridge. He was obviously distressed – he kept hitting his chest repeatedly and looked exhausted. I told him to go home and rest. But he said he needed to keep moving, he had so much energy, he needed to walk some of it off. I walked with him a while but couldn't keep up. Perhaps I should have kept going…

> Tried ringing [names of mental health hospitals in London] they all denied he was there, but not sure if [Name of hospital] was telling the truth…

> [Name of hospital] was the last hospital Andy was sectioned in…

> I am thinking he must be in the bin [asylum] but I don't want to go around asking questions and drawing attention to his disappearance cos he may be in hiding from section. Remember he did that last time, and went to Scotland??

> It is possible that Andy is lying dead on the floor of his flat. But as he is under the tender care of 'care in the community' I think we would have heard by now…

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[302] Although not religious, Andy participates in a support network run by churches in London. He receives food from and attends events at his local church.

[303] This complicated Andy's situation. Eric visited Andy daily during the two years he was hospitalised under section and sat in on all of his appointments and ward rounds. Eric has a key to Andy's flat and checks on him if he fails to answer the phone. Mental-health wards are not permitted to disclose information about patients unless they are kin or an advocate. Eric is listed as Andy's next of kin and as such is the only person legally entitled to have information about his whereabouts and treatment. Kin/advocates become involved when a patient is deemed not to have mental capacity to make their own decisions. Unlike Andy, Eric is very predictable person as he is a 'creature of habit'; the two of them are very close and therefore their simultaneous disappearance was concerning.

> It is clear that the disappearance of Eric and Andy is interlinked, and it is puzzling. One of them might have killed the other. I think there was some mention of a row between them…
>
> I'm currently at [name of drop-in centre]. Nancy has an information network which rivals MI5 and knows several people who lives in Andy's block. She is going to make discrete enquiries...

Finally, it was decided that someone should check whether Andy was at home and Janet and I volunteered for this role.[304] To reach Andy's flat we had to persuade his neighbours to let us through two sets of access-coded doors. However, the corridor outside the flat was locked and we were unable to approach his front door.[305] We rang a neighbour on the telecom. She said she had not seen Andy in a long while and thought it likely that he was on holiday. We left without seeing him. Bryan went to his flat a couple of weeks later, but he too was unable to gain access.

I went through my field notes looking for clues as to where Andy might be. In them, I saw that my last meeting with him contained hints of a life unravelling;

> Andy says he has lost his laptop charger, so he can't use the computer to write – his main way of keeping busy and finding purpose. He also lost his freedom pass, so is stuck at home.[306] He's worried that he is at risk of becoming ill because of the state of his flat. He explains that it is filthy, that there are dirty plates everywhere. 'Can't you tidy it?' I ask. 'No, I lost those skills in hospital'. I ask him what he means. He talks about how he learned to cook and clean after leaving home at age18…But being in hospital made him lose those skills - he has spent years having other people do things for him. I ask him if he knows anyone who can help him clean the flat - perhaps a friend? He says no… Eric 'doesn't do cleaning'… Andy abruptly changes the topic of conversation and mentions having approached various actors about turning his memoir into a film and the parts they might play. He says he

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[304] Janet came up with the idea of posing as social workers in the hope that this might encourage neighbours to provide us with answers to our questions and to avoid arousing suspicion about the circumstances surrounding Andy's disappearance. We walked with an air of confidence, dressed smartly in suits, and carried clipboards.

[305] An A4 sheet of paper was posted on Andy's door, but we could not read what it said.

[306] A travel card for people on disability benefits that enables them to use most London transport for free. Without it, many cannot afford to use transport.

would like David Tenant to play his part. At first, I think he is joking, but he then explains that he visited Tenant's agent (who turned him away and told him that he should email). Andy says David would be right for the job, because of his Scottish heritage, and the fact that he has twice starred in films about mental illness-*Asylum*, and *Mad to be Normal* (Fieldnotes 2018).

The search for Andy continued for months; concern for him was increasing, especially given the worry that he might have been sectioned and was being held in hospital against his will and without visitors to provide support and/or ensure he received fair treatment. Some of the activists who had themselves experienced detainment said they found this possibility unbearable; one explaining that it made her feel physically sick. When Andy's name came up during meetings, participants would look at each other dejectedly, with much sighing, frowning, shaking of heads, and muttering, the consensus being that 'he's in the bin'.

It was not until after I had left the field that Andy was finally found. He had indeed been sectioned, having walked into a pub in Mayfair one day and shouted at the windows. A policeman had accused him of violence and the case went to court, although he was not sentenced.[307] After six months in hospital, some of his restrictions were removed and his mobile phone was returned to him. He immediately texted SAP members to inform them of his whereabouts. Eric was still missing. Andy was unaware of Eric's disappearance and had no idea where he was.[308] Lyndsey, the person who had argued with Andy and so publicly berated him, was the first person to visit him in hospital and went back to see him numerous times. However, after a few weeks, she came to a SAP meeting looking exhausted and, with her head in her hands, reported that Andy would shout and "hurl abuse" at her during these visits. He brought up their previous argument and accusing her of racism, said she should leave and get lost. However, she continued going back. She

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[307] A recording of the incident on the pubs' security camera revealed that Andy was innocent of the charge that he had been verbally abusive. This was important because people are sent to maximum security wards if accused of criminal behaviour/face criminal charges. These have the highest levels of restrictions (hence why Andy was allowed no phone or contact with anyone other than his listed next of kin).

[308] As Eric was listed as Andy's only contact and advocate, the hospital was unable to notify others, friends or family. In light of Andy's conduct in hospital (such as writing 'Help, I'm trapped in hospital, get me out' on his Facebook status), he was subject to additional restrictions and not allowed a mobile phone. Restrictions on the use of personal devices are common on psychiatric wards, the amount of time they are restricted for depending on the patient's behaviour. Many months after Andy was found, it was discovered that Eric had been in prison for a minor conviction. He was released in 2020 and resumed his support for Andy.

sighed and, wringing her hands and staring blankly ahead, explained that these visits reminded her of the stress she experienced during her own incarceration. She was worried that visiting Andy was causing her mental health to deteriorate and that she might 'spiral' into 'an episode'. Janet looked sympathetically at Lyndsey, and said she wished she could help, but visitors are only allowed in one at a time. Even though Lyndsey felt she was incapable of helping Andy, she was determined to visit him again. In disbelief, I asked her why she had decided this. Blinking incredulously at me, she replied, "No one should be left behind". The search for Andy reveals the lengths activists are prepared to go to in ensuring that fellow activists maintain their autonomy and avoid unwelcome intervention - out of respect, to demonstrate their value and personhood. However, these efforts are often in vain, as in this case. Mutuality seems to reach its limits when confronted by the power of mental-health bureaucracy. For example, due to the hospital's data-protection protocols and with Andy's named advocate, Eric, also absent, activists were unable to access essential information regarding Andy's whereabouts. Likewise, in hospital, Andy was allowed only one visitor per day, limiting the amount of support he could be given and putting the weight of support on one individual at a time. The search also shows that activists sometimes pay a very high emotional price for their efforts, indicating that mutuality can create—not just alleviate or prevent—suffering.

Then there is the fact that, even though originally conceived of as a collective effort, the responsibility for finding and supporting Andy fell primarily on two individuals. This situation reveals the ambiguity that prevails in activist relational practices, insofar as the collective and interpersonal spheres are not always aligned and nor are the responsibilities of individuals self-evident. Given the commitment to cultivating an environment in which individuals should feel free to be themselves and speak and behave as they wish, without constraint, activists generally avoid placing explicit expectations on each other. This means that there can be a lack of clarity around both the purpose of activist networks and the responsibilities of their members in providing care and support. As one interlocutor reflected, "Although [organising] groups aren't necessarily cast in the role of support groups, the support element is a big part of coming together. How can solidarity be realised if people aren't genuinely concerned about each other's welfare?" Of course, interlocutors were often very concerned about one another's welfare, which I demonstrate in this chapter.

One consequence of this open stance is that whatever activists do for their peers must ideally be done willingly, and without obligation.[309] Bryan clarified this to me during one of the Covid-19 lockdowns. I mentioned to him that Greg had been sending me texts in which he was concerned that Covid-19 was connected with climate change and that the world is coming to an end. Bryan responded, "I think he just needs to talk to people… but you're under no obligation to reply". Even though the lack of a sense of obligation may have been commonly discussed by activists, in practice, the extent to which activists feel compelled to aid others varies greatly, with some seeming overwhelmed or hurt by their caring contributions. This is evident in the case of Janet and Lyndsey, who were themselves struggling mentally; in trying to absorb responsibility for Andy, Lyndsey's own mental health deteriorated. The likelihood that enacting mutuality will worsen interlocutors' distress, appears greater when it invokes memories of their own experiences of biomedical treatment. These findings resonate with research by Cubellis (2018) on peer support in a recovery centre in the eastern United States. Cubellis explores how, despite the rhetoric surrounding peer support as being more 'democratic', 'free of asymmetrical power dynamics', and 'transformative' than TAU, supporting peers can 'wound' the caregiver. She writes, "Peer psychiatric support at respite centres is a kind of labour taken up by a previously marginalized population in the service of affective needs not met by psychiatric treatment-as-usual." (2018; 4-6). She suggests that in trying to compensate for what are in fact structural constraints—a lack of affordable, secure housing for people in psychiatric crises for example—peers can become more distressed. Further, even though a shared sense of 'vulnerability' and 'mutual hurt' may allow peer workers to connect with those they support, this can result in them feeling alienated and powerless given these constraints. The personal (his)stories they draw on in undertaking their everyday care work can feel redundant. In this context, Cubellis notes, "Care can wound those who offer it up to a rigid and unfeeling system, it can wound when it demands exposure of one's own hurt, and it can wound when that exposure is seized on as a means to mitigate the fissures in a larger broken system" (2018; 11). However, unlike peers at the respite centre, 'wounding' may also constitute relatedness, as I will now demonstrate.

There were other aspects of the search that were difficult to comprehend, particularly why Lyndsey would risk her own mental health for the sake of someone who she actively dislikes and has spoken out against. At first, I read her willingness to brush aside her

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[309] Although in practice, activists did feel obliged to support one another, as I show in this chapter (and discussed in the introduction, when I introduced the notion of generalised reciprocity). It was a preference that activities would be undertaken without obligation.

differences with Andy as a signal of activists' commitment to sustaining individual autonomy, whatever the odds. However, as I witnessed more and more examples of interlocutors tolerating aggression from and absorbing the pain and distress of, others, I came to understand this process differently. Initially I perceived the frequent arguments between activists as potentially disruptive of their sense of mutuality—although I also noticed that these arguments were given space in a way that seemed exceptionally forgiving.[310] Activists seldom intervened in each other's conflicts and would let them play out, a norm that applied not just in meetings but all contexts. Eventually, I came to understand that extending unconditional support to others, regardless of their conduct, may not be a wholly negative experience; though Lyndsey found visiting Andy in hospital painful, leaving him alone would likely have caused her even greater distress. Later on, Lyndsey commented that given she was a visitor to, rather than a patient in, the hospital this meant she was in control and free to leave when she wished, a circumstance that helped her process her feelings about being incarcerated in the past. Thus, it seems that activists' experiences of other people's suffering can become tied up with, even indistinguishable from, their own. However, being affected in this way is not necessarily inherently harmful, so much as a response that feeds back into the project of mutuality. Similarly, arguments between individuals being aired in the presence of a group may potentially create a sense of intimacy and containment that comes from bearing witness to struggle and journeying through conflict as part of a collective. This pattern resonates with Reece's (2015: 37) understanding of kinship; she notes that "conflict and crisis are not simply unfortunate things that happen to families and are best avoided; they are continuously produced by kinship, and produce kinship in turn".[311] Moreover, given that many activist networks have remained in existence for decades and participants spend

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[310] As discussed in chapter 5, activists place a strong value on individual autonomy and self-determination, including a stance of non-intervention when it comes to individuals expressing their distress. Worldbuilding involves creating space for unrestricted self-expression, interlocutors hold the expectation that individuals should go through whatever they need to, regardless of the consequences and un-moderated by ideas about what might be helpful or distressing for others. One aspect of this I noticed early on in fieldwork was the significant flexibility regarding the presence and commitment of interlocutors at activist group meetings and other events. Activists move freely between events and groups; dropping out, stepping down, falling out, leaving, making up, connecting and coming back together again. One of the most striking aspects of this flexibility is that arguments and fights are given space in a way that seems incredibly forgiving, yet at first seemed counterproductive from my point of view (see chapter 4 for ideas in the psychotherapeutic literature concerning consistency and predictability constituting safe places). Individuals did not often get directly involved in one another's conflicts – letting them play out - and in meetings, a similar norm applied.

[311] Póltorak has pointed out that due to a historically disproportionate number of professional anthropologists originating from middle- and upper-class backgrounds, there is likely to be a bias in the way anthropologists interpret conflict (particularly within families), rendering it a negative phenomenon (pers comm, 2021) (see also Spencer 2000).

years together, moving through different disputes and experiences, the affective aspects of witnessing arguments can build up over time. Accordingly, activists would often refer to old disagreements almost as though reminiscing over fond memories. In this sense, conflict can be seen as an expression of safety, security and relatedness and, by the same token, wounding may be regarded as symbolic and constitutive of the kind of mutuality activists enact.

5.5 Chapter conclusion

In this chapter I explored activists' relational practices and ways of being-with one another. I began by summarising the difficulties I encountered in researching this topic and explained why this might be. I showed that activists' relational practices do not adhere to binary notions of care or exchange that characterise biomedical relations of care. In fact, activists' approach to support is shaped by an explicit rejection of the organisation and enactment of care in biomedical settings. Further, much about activists' interpersonal and collective interactions remains unspoken—and these interactions do not always seem deliberate or intentional. In conceptualising activists' modes of interaction, I deployed the concept of mutuality, which draws on the work of Schlecker and Fleisher (2013). Thus, support is conceptualised and enacted among activists as something born out of a common desire to live a life without social hierarchies—a kind of 'background operation' that is part of the business of living in a world one necessarily shares (Schlecker 2013; 2). In this way, mutuality among activists involves an orientation toward the other (in a collective sense), as well as to oneself. Whether intentional, explicit or implicit, activists' modes of expressing mutuality are in stark contrast to the kinds of relationships that are rendered possible within biomedical spaces. Activists' primary concern is to assist peers in their struggle to overcome their mental health challenges and remain autonomous and free of unwelcome intervention by service providers and family.

I argued that the concept of mutuality effectively depicts the three central features of activists' relational practices: attunement, balance and unconditional support for others. I made this case by starting with the empirical evidence for attunement. I suggested that attunement arises when individuals come together to share feelings and experiences, presence and (inter)subjectivity, so that people who were once strangers become bonded. In the case of activists, these experiences centre on, among other things, mental distress,

harsh compulsory treatments, social prejudice and economic precarity. The resulting sense of commonality gives activists a close understanding and acceptance of their peers that persists despite highly dispersed social networks and volatile inter-personal relations. Often attunement entails subtle acts, such as taking time to listen when a person speaks or sitting alongside them when they are distressed. But it may mean more active engagement, such as offering practical assistance and advice. Nonetheless, it would be inaccurate to imply that attunement is easily achieved, as it involves continuous negotiation and meaning making, as well as respect and empathy for the individuality and singularity of others.

I maintained that interlocutors reject the unequal relationships and dependency embedded in the formal mental-health model, perceiving practices such as sectioning, forced internment and treatment as a negation of care. This manifests through activists' fear of official and/or labelled care roles, in which care is entangled with expressions of power and inequality. Thus, in claiming that balance is the second central feature of activist mutuality, I showed how activists seek to avoid reproducing what they perceive as the corrosive power dynamics of formal services. Activists support one another amid multiple daily pressures, in a context of precarious health, punitive welfare regimes and structural failures. Mutuality forms important bonds between people but it is also complicated by social obligations – and social debts – including the state's historical 'debt' incurred though its failure to care (Han 2012). Thus, equality, co-presence and reciprocity are central to interlocutors' enactment of mutuality. As well, in their view, caregiving and care receiving should emphasise and not threaten autonomy; it is not about 'looking after' or 'providing for' someone but comes with the understanding that the person you support has agency and the right to act autonomously.

In highlighting the third key feature of mutuality, I proposed that, ideally, the trust and acceptance embedded in activists' relational practices should be extended unconditionally, regardless of the circumstances of the caregiver, or the degree of familiarity with, or conduct of, the recipient. However, I do not suggest that activists' relational practices are free of contestation or conflict; it is clear that mutuality can be both onerous and painful. I cited as an example how individualising health systems isolate activists from one another and from activist spaces so that supporting one another through TAU can incur feelings

of extreme powerlessness.[312] Similarly, despite intentions to spread the 'burden' among activists, often providing support falls on certain individuals, intensifying their feelings of personal responsibility and invoking difficult memories of their own vulnerability and distress. Indeed, for some activists, other people's anguish can become intertwined and even interchangeable with their own suffering.[313] That said, I conclude that conflict and wounding may not simply be a source of pain since experiencing distress through the suffering of others can also enhance mutuality. To this end, I contend that mutuality is about more than attunement and support and also involves estrangement and distancing. The experience of living through distress intersubjectively maintains social, material and affective links among activists; the suffering of others serving as a reminder of shared experiences. Thus, the circulation of hurt that interlocutors experience as a result of listening or witnessing others' distress should not be dismissed simply as negative occurrences, rather they are also constitutive of mutuality as it is enacted and experienced collectively.

From the evidence I have provided it is clear that as far as activists are concerned, care, as a dynamic set of acts and practices, is loaded with political, social and historical ambiguity. Activists support each other in ways that respond intimately to individuals' concerns in the present, as well as building on past experiences of suffering and oppression. Relations necessarily involve an affective dimension that interlocutors perceive to be missing in clinical encounters. Support is preferable when it is enacted collectively and is free of financial considerations, regulations and other institutional processes. Thus, through mutuality, mental-health activists try to resist the individual orientation that characterises NHS mental healthcare and discourse in the UK. This means that when it comes into contact with services and treatment approaches that replicate the self/other dyad, wherein responsibility for caring is placed on individuals, the project of mutuality can 'wound'. Intentions to be *otherwise* can be undermined by adverse structural

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[312] Here I am referring to what is often described as 'neoliberal' healthcare contexts in which persons are treated as individuals, rather than members of families, groups, or communities. Anthropologists such as Cook (2016) Armstrong (2017) and Singer (2017) have examined the impact of neoliberalism on approaches to mental health care in London. They argue that self-taught techniques such as mindfulness promote 'responsibilisation' of the individual, in turn deflecting attention away from socioeconomic catalysts of distress towards individual cognitive functioning. Whereas some suggest that the focus on thought management facilitates individual control and empowerment, others argue that this approach is misplaced, insofar as it absolves the state of responsibility for individuals in distress.
[313] As in post-invasion Iraq (Al-Mohammad and Peluso 2012), caring among activists is considered neither a social 'good' nor a moral judgement; it is more an anticipated necessity than an expected norm. It is not labelled or compartmentalised as support but rather a way of life.

conditions and enforced interaction with services that employ individualising support models. The physical environment of biomedical healthcare as a set of conditions can initiate distress in individuals and prevent support from being a shared responsibility of the community.

Chapter 6: The Politics of Healing and a Healing Politics

6.1 Chapter introduction

Thus far, my thesis has focused mainly on activist sociality and its place in healing mental distress. However, I refer to interlocutors as 'activists' throughout, a term that quite a few use to self-identify and one that underlies the political intent behind their mobilising and their networks. Therefore, this chapter focuses on activists' political aims and organisation. In it, I argue that mental health activism centres on much more than a quest for change, whether this be about bringing an end to the power imbalances and exploitation associated with capitalism, or campaigning for more just and compassionate services. In making this case I am suggesting that the 'political' is a not separate terrain; rather it is infused in activists' everyday ways of interacting and being, as previous chapters have demonstrated. As Razsa reflects; "like anthropologists, anarchists understand the political not as a separate sphere, but as permeating every aspect of social life" (2015; 20).[314] Moreover, in the chapter I suggest that these everyday ways of doing politics are infused with a propensity towards indeterminacy, and that indeterminate politics also heal.

In the chapter I show that mental-health activism is sometimes outward-looking, and involves engaging with service providers, state officials and the public at large through collective action. This is rather different from collective and interpersonal acts of mutuality that are more attentive to supporting fellow activists. But to argue that the collective action underpinning mental-health activism is inherently political is not to suggest that it conforms to the procedures, ideology or structures—voting, membership of and campaigning for political parties etc.—typically found in democratic societies. Far from it, not only does most mental-health activism occur at the margins of existing political norms, values and institutions, but it openly challenges these structures and processes through its adherence to "new plans and ideals for living" (Crossley 1999; 810). Then again, activism can appear

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[314] Indeed, without ever making explicit reference or connections to anarchism or filo-anarchist affiliations, many mental-health activists have engaged widely with anarchic tendencies, such as 'voluntary cooperation and free associations that are non-hierarchical, being focused on communal good,' (Willow and Yotibieng; 2020, 734) including other groups and movements such as Occupy (see also Graeber 2009 Krøijer 2020 Juris 2008 etc.).

quite nebulous and indistinct, often rejecting the kind of regulations, leadership and tangible objectives that characterise many political groupings found in the UK for example. For interlocutors, maintaining an (indeterminate) political stance is about refusing to be defined according to predetermined political goals and objectives. As such, activism emerges not so much as a distinct and recognisable field of action, but more through the ways in which interlocutors respond to their constrained circumstances—particularly their perceived lack of agency and control in situations of unrelenting uncertainty. In light of these conditions, I conceptualise activists' modes of political action in terms of indeterminacy, as noted in the introduction to the thesis. Borrowed from recent anthropological work on social movements (e.g., Zigon 2018; Raschig 2016; Cubellis 2020), I draw from prefigurative and 'otherwise' frameworks. The term 'otherwise' draws attention to the fact that actors who confront severe resource and structural constraints are unable to 'live the [exact] change they wish to see in the world'.[315] Thus, I examine the small, sometimes intangible, everyday changes activists are able to achieve, as well as their ways of being. In the process, I maintain that their political actions can be seen as an attempt to counter the constant uncertainty they experience as much as the individualism, isolation, and asymmetrical power dynamics that prevail in the mental-health and social-welfare systems and in society at large. Indeterminacy highlights how in such circumstances actors reimagine and re-configure their current conditions and thus, build worlds. In other words, activists embody in their social lives 'the change the movement seeks" (Edelman 2001; 289). In doing so they create different possibilities for living; in this sense, activists' political power is about *becoming*.

In making the case for framing activism as a politics of indeterminacy, I draw on the example of an RMH-led demonstration that took place in November 2018. This example illustrates the structural and personal obstacles that interlocutors contend with on a daily basis and highlights how the uncertainty of their existence leads them to continuously adapt their expectations and change their political aims. Analysis of these data leads me to suggest that those whose lives are constantly disrupted by illness and material insecurity know that whatever their hopes, things cannot be expected to go to plan. They experience the collapse of what Bourdieu terms the 'biographical illusion'—the assumption that life can follow plans and also that coherent decisions are key to life's

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[315] This phrase is attributed to Mahatma Ghandi and has become the slogan for prefigurative political movements

stages (Bourdieu 2000).[316] As Rapport puts it, illness in particular is often experienced as an interruption in rhythm; a change in personal and social expectations (pers comm; 2021).

The chapter is organised follows: In section one, I describe the objectives underpinning an RMH demonstration, which took place in November 2018. The second section centres on activists' modes of political organisation and engagement, which I illustrate through further consideration of the planning and management of the demonstration. I explain that, despite the careful preparations, the event did not pan out as hoped or anticipated by those involved. Their political actions were compromised by personal, social and structural conditions beyond their control, such that they were required to continuously adapt their goals and keep their horizons open, a strategy that I frame in terms of 'disclosive freedom' (Zigon 2018). I take this argument further in the third section by showing how the outcome of the demonstration was reconfigured by activists in its aftermath, such that the event came to be perceived as a major success. In section four I extend this discussion further, highlighting how, by navigating ambiguity and managing expectations, the act of mobilising can bring its own rewards, insofar it creates possibilities for connecting with others as well as for self-realisation and personal transformation. With these benefits in mind, I suggest that indeterminate political engagement can be conceived of as contributing to, or essential to, healing. However, in the final section I show that the demonstration had adverse consequences for quite a few of those involved, inasmuch as it had a series of affective and somatic impacts which required extensive periods of recovery. This finding resonates with the point I made in the introduction to the thesis about how chronic stress accelerates the 'break-down of bodies and minds'; what Lurhmann calls 'social defeat' (Lurhmann 2012). Echoing Lurhmann and Raschig, I argue that in "a world which [one] must constantly be healed from" and given conditions of "exhaustion and compromised dwelling" (Raschig 2016; 30) interlocutors become ground down.

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[316] With this concept, Bourdieu critiques the genre of biography. He coined biographical illusion to refer to research contexts specifically, which he argues are founded upon artificial creations of meaning. I use his framework to refer to narratives and framings of life in general. (Others have also argued for understanding illness in similar terms, such as biographic 'disruption', 'abruption', or even 'repair' (c.f. Bury 1982; Locock et al. 2009).

6.2 'We Demand': a manifesto for change

In chapter 2 I outlined some of the political aims of mental-health activism, describing the key objectives of the three London networks that I participated in and studied most closely; RMH, SAP and FLL. I clarified that there is a long history of mental-health activism in London, and that quite a few networks remain in operation today. Some of these networks have extremely specific objectives and others, longer-term, more generalised, goals--with the understanding that intentions are not stable, or always coherent, and that actions do not necessarily provide evidence of prior intention (Johnson-Hanks 2005). This was followed by a brief discussion of the views of individual activists, as expressed in interviews, and at meetings and other events. In the section that follows, I focus on the aims behind an RMH-initiated protest. One of the largest mental-health activist demonstrations in some years, this event illustrates the kind of issues that motivate interlocutors to take political action.

The RMH demonstration

It is against the broad backdrop of mental-health activism described in chapter 2 that interlocutors mount campaigns. It was Lissa's idea to organise a protest on the 18th of November 2018. She had joined a mailing list[317] whose subscribers received an email in the summer of that year notifying them that there was to be a joint NHS--parliamentary review that day, the aim of which was to agree on spending cuts to the UK's mental-health services as a part of an efficiency drive. The meeting was to be at The Royal Society in central London, attended by members of parliament and executive directors of NHS England, including NHS England's National Clinical Director for Mental Health. [318] Outraged by these plans, Lissa initiated an email exchange with fellow RMH activists, in which the review was greatly disparaged. One activist commented, "profiteers and welfare/NHS cost cutters will be discussing mental health services that are designed to benefit employers over the wellbeing of people who live with mental distress". Lissa called RMH activists together to help organise a demonstration outside The Royal Society on the day of the meeting. The demonstration involved considerable planning, leading up to a day of 'action' intended to disrupt the review meeting.

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[317] Posing as the governor of a mental-health ward.
[318] How to maintain care quality and efficiency in the face of 'essential' spending cuts was high on the agenda, as were 'priorities and best practice' in mental healthcare, 'improving access to evidence-based treatment' and addressing the 'unwarranted variation of mental health services'.

It was agreed that it was essential to build public support for the protest and to inform meeting delegates of RMH's views in advance. To this end, a decision was taken to write a letter, together with a manifesto, for distribution to members of the press and organisations with an interest in mental health.[319] Entitled, 'We Demand', the letter reflected activists' experiences of mental-health provision in the UK, outlining the government's proposed cuts to services, explaining why activists opposed this move and what reforms they sought. The letter comprised a mix of quite concrete demands and broader objectives that prefigured 'other' futures. It called for a public inquiry into "the deeply harmful impact" of mental-health services[320] and a change to the culture of mental-health provision, with a focus on delinking mental-health and social-welfare provision and long-term user-led support. More specific demands included: the cessation of the 'conscious cruelty' of Work Capability Assessments; the nationalisation of research into and manufacture of drugs[321]; a public inquiry into institutional racism, sexism, classism, ableism, and LGBTQ+ discrimination in services; a fully funded national 24-hour suicide prevention and support service; and an independent body to oversee and investigate the waiting lists of CMHTs and for CAMHS.

Although the demonstration was to be aligned with the 'We Demand' letter and RMH's broader goals, I was not clear what RMH activists hoped to achieve by protesting and posed this question to them at one of the planning meetings. There were several responses, one being to "prevent the meeting from taking place at all", another to "prevent spending cuts going ahead" and a third, more specifically to "initiate an enquiry into treatment on psych(iatric) wards". Lissa said, "We need to stir things up….and make them realise that they can't make huge decisions without consulting people like us. We will always make our presence known". Will added that he thought the aim was to show the government that they could not get away with making spending decisions without understanding the needs of those directly affected. There was agreement that the demonstration was a way of "showing people in power that we are not to be forgotten" (Janet, email).

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[319] Unfortunately, the manifesto is not appendicised here to avoid breaches of anonymity
[320] See chapter 2 for a discussion of these assessments which are designed to determine the ability of a person with an illness to work.
[321] So as to eliminate the profit motive.

From the diverse and sometimes very generalised and ambitious political aims expressed by interlocutors during my time in the field, I came to appreciate that having coherent, tangible goals is not necessarily a prerequisite of mental-health activism. In fact, keeping campaign objectives open and ill-defined has many advantages, as I show in section three. Having briefly touched on some of the aims interlocutors *did* articulate, in the next section I outline the barriers activists commonly experience in their attempts to effect change.

6.3 "Bear with me": Patience and open plans as part of disclosive freedom

Here, I illustrate activists' mode of political organisation and engagement by describing the steps leading up to the RMH protest, and what happened during the actual event. In doing so, I suggest that greater importance seemed to be attached to the process of organising the protest—and particularly to involving as many RMH activists as possible in that process —than to either setting or accomplishing its objectives. I start by underscoring the detailed work involved in preparing for the demonstration. I go on to show that things did not go to plan and highlight the many reasons why. Finally, I explore activists' responses to the barriers they confront, conceptualising these as a form of 'disclosive freedom' (Zigon 2018); or, in other words, a way of navigating uncertainty in a context where activists' political power is becoming.

Planning the demonstration

Even without a clear consensus on the objectives of the protest, RMH activists were extremely busy in the weeks preceding November 18th preparing for the demonstration. Plans evolved daily and working frantically and energetically, they typed up notes and passed messages back and forth, no detail left unturned. Information about the event was shared with other activist networks with the intention of getting them involved. The wording and ordering of the text in the 'We Demand' letter was discussed, fine-tuned and voted on frequently, until everyone was happy with its content. Participants were given an opportunity to express how strongly they approved or disapproved of each of the demands. A significant proportion of RMHs' modest budget (consisting of personal

donations) was spent printing the document and people travelled all over London posting them through the letter boxes of local mental health services, and pinning them to noticeboards in churches, community centres and venues, as well as uploading them online. So as to maximise their impact, one group of activists pored over printed google satellite images of The Royal Society and its grounds, meticulously detailing where protestors should stand and at what time. When deciding on demonstrators' roles, careful consideration was given to individual preferences, abilities and temperament. It was agreed that people with less confidence and less experience of speaking in public should stand outside the entrance and lobby the delegates as they arrived, while a smaller group of more self-assured activists would attend the meeting undercover.[322] The latter group was assigned the task of calling for delegates to answer the demands listed in the letter and disrupt the meeting more generally. There was some discussion around who might not be well enough to participate on the day and suitable activities, for example initiating a twitterstorm, were identified for these individuals.

Hours were spent brainstorming which organisations beyond activist networks might have an interest in mental-health provision and therefore in participating in the protest. The resulting list included civil servants, academics, members of the press, politicians (such as the Liberal Democrat's spokesperson for health) as well as allied organisations, for example 'Psychologists and Counsellors Against Cuts'. Proposed invitees were split into groups, and we were each assigned a group and given responsibility for inviting them to participate. Information about the demonstration was shared well in advance, partly to enable those with disabilities to plan their travel. It was also agreed that to attract public attention a strong visual impact was needed. So, Steve borrowed a sewing machine and together with a volunteer from Disabled People Against Cuts (DPAC), made a large cloth banner. Emblazoned in red, the banner bore the words 'Welfare Cuts Kill', along with an image of a clenched fist wrapped in a bloody bandage and raised in salute. The picture was intended to symbolise the many suicides that have been associated with welfare sanctions and depleted services (see DPAC 2012).

One week prior to the demonstration, I attended a banner and poster-making session at Lissa's house. With all the promotional work we had done, Lissa predicted that the demonstration would attract a large number of participants, likely more than a hundred.

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[322] The tickets were purchased using the RMH fund which is pooled from personal donations

She announced excitedly that RMH protests "can't be kept secret because we have such a high profile" and, "The protest will be too big to keep quiet." Lissa's enthusiasm was infectious and, in anticipation of a high turnout at the session, we agreed that there was much work to be done. Given this momentum and having sent invitations to help with the poster-making to several activist networks, she expected a good number of volunteers to turn up. She did a large grocery shop, using donation funds, so as to able to feed everyone. However, when the appointed time came, Julie and I were the only ones to appear.[323] Although I was surprised by this turn of events, the others were undaunted and the three of us set eagerly to work; we remained busy late into the night, until past three am. We created slogans and Julie typed them onto posters, which she carefully printed out. I pasted and glued the posters onto cardboard placards. Meanwhile, using three different devices simultaneously, Lissa sent out press releases and tweeted our campaign messages far and wide.[324] She also cooked us meals and made numerous pots of tea. In the end, we managed to make sixty placards. Talking excitedly, Julie exclaimed that the demonstration was "gonna be massive" and reminisced how making the placards reminded her of when she organised birthday parties for her (now grown-up) son. Lissa commented that being so creative prompted memories of her time as an undergraduate at art school.[325]

Given the poor turnout, I found it hard to understand how Julie and Lissa could remain in such high spirits, especially given Lissa's optimistic projections on attendance beforehand. They seemed to adjust their expectations very quickly that evening; but I was not so upbeat. My hands were sore from cutting and gluing posters, and my eyes dry with fatigue. As time went on, I became increasingly concerned that, to get home, Julie and I faced hours of travel by night bus. Eventually, in frustration, I complained that there were only three of us to accomplish such an enormous task. Taken aback, Julie replied, sharply, "Steve's resting and others are writing speeches. We're all preparing in our own ways…. We're working harder than those with jobs". She went on to explain that organising a demonstration is complex and means being open to undertaking a wide range of tasks, not just basic practical chores like poster-making, but ones that also respond to individual needs. She pointed out that this involves concerted mental preparation. From her

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[323] I saw this as an unexpected development, as discussed in the next section.
[324] The signs bore messages such as, "Nothing about us without us", "End the Corporate vulture's feeding frenzy", "End Psychiatric Abuse" and "Stop the Chemical Cosh".
[325] These comments were particularly poignant in light of the fact that Lissa has been forced to give up parenting and Julie ceased her education because of episodes of acute distress and hospitalisation.

commentary it was evident that Julie avoids making assumptions about interlocutors' potential for engaging actively in protests, there being diverse roles and types of contribution.[326] The observations made by Julie and Lissa that evening were the first time I was made aware just how laborious and challenging practically and emotionally mental-health activism can be for those concerned. It was also the first time that realised that conserving one's energy in readiness for the event is understood as a legitimate way to prepare. As I was also yet to learn, the banner-making session was the first of several events connected with the demonstration that, in my mind, 'failed' to live up to expectations.

The demonstration

Any uncertainty about activists' commitment to campaigning that I may have felt following the banner session was greatly increased by what happened during the demonstration itself. That morning, I was awakened by my alarm at 5 am and battled my way through rush-hour traffic into central London. Arriving, at the spot we were to meet at 7.45am, as planned, I found I was alone. Again, I was disconcerted by this and unsure what to do, checked my phone several times to make sure that I had not mistaken the time or location. It was bitterly cold, but I decided to remain, frantically texting and calling the others as I waited for them to arrive. In the meantime, MPs, NHS officials and other meeting delegates began to arrive, and walked past me into the venue. Few of my calls were answered and those people who did reply said they were on their way. Eventually, at around 8.15am, a number of people began to gather nearby, although the RMH protest organisers were not among them. Indeed, I barely recognised anyone. We stood awkwardly for some time without speaking or attempting to enter The Royal Society; a small group of strangers with a pile of makeshift placards tidied away at our feet.[327] It began to rain, and puddles formed on the ground, so the placards were soon soaked, and the ink began to run. Eventually one woman shouted for us to 'get our banners out' and 'move closer to the entrance' so that we could hand leaflets to the delegates as they arrived. However, the review meeting had begun at 8.30am, and by now it was almost 9am, so we had already missed the opportunity to canvas the majority of delegates, who were already inside. Moreover, the RMH activists had yet to appear and there were no

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[326] Activism is often considered by interlocutors as a mode of labour; activists commonly highlight the value (particularly social) of the different kinds of 'work' they undertake.

[327] We did not have the official RMH banners and placards at the beginning of the demo, but other activists had bought their own.

protestors inside the venue. Eventually, sometime after 9, Julie, Lissa, Austin, Will, Alexa and Steve arrived separately. Bryan and Janet appeared much later. It was unclear who, if anyone, was leading the protest. By this time, the whole event felt to me like a significant anti-climax.

Figure 7 "Arbeit Macht Frei" poster, 2018

Figure 8 Abandoned/ unused banners and posters at the demonstration outside The Royal Society, 2018

The Royal Society's security guards—two large men and the operations manager—approached and asked us, rather gruffly, to leave. When none of the protestors made a move, the guards became frustrated and threatened to call the police. But a few more protestors began to arrive and as the numbers grew, so did our confidence. Several protestors started to film the event on their phones and, as if to finally assert our presence, they started tying placards to the fence surrounding the building and leaning others against rucksacks on the ground. Eventually, the guards and protestors began to argue. Someone shouted, "you can have your private property back when we leave" and Greg started swearing at the guards. At this point, trying to quiet Greg down, a woman from 'Psychologists Against Cut' told him sternly not to use such language. This moment seemed to mark a turning point in the demonstration. Initially there had been much discussion about the law on trespassing, knowing one's rights, where to stand during the protest and what to do if carried away by the police. But by now people were no longer talking like this and I wrote in my field notes that the protestors appeared extremely relieved and had begun to relax. Reflecting on the tense atmosphere that had prevailed at the outset of the demonstration made me appreciate just how nervous protestors had

been about the possibility of being arrested, a concern that apparently dissipated over the course of the day.

Something else I noticed was that none of the RMH activists—not even Lissa—took the trouble to explain why they arrived so late that day. Curious about this, I commented that, as far as I was concerned, all our careful planning for the demonstration had been in vain. The others responded to me in turn, each one clarifying why they had been so late by listing the many obstacles they had faced. Julie and Will explained that they had had to wait until nine-thirty to get the underground because their freedom passes (a free travel card for people with disabilities) are not valid during periods of peak travel. When Julie entered the underground station, she discovered that the banners she was carrying were too large to fit in the disabled lift and was obliged to find another means of transport. Will was unable to get out of bed that morning until the lethargy induced by his anti-psychotic medication had worn off (it took two hours). Steve was so unused to being up and about in the mornings that he failed to anticipate how long getting ready to leave the house and travelling to the venue would take. Since it was rush hour, Alexa had found the underground so stressful that she had a panic attack and got off the train to calm herself down. She was at a station outside London at this point, and waited there until she felt well enough to resume her journey. Whilst listening to Alexa, I receive a googlegroup notification from Mike which said, "I have a benefits assessment no one told me about, so I can't come today - I don't want to spend money travelling into London until I have an income again". Steve replied with the message, 'Solidarity with you mate.' As the RMH activists shared their reasons for being late, I became increasingly embarrassed about having expected them to explain themselves. However, I did also notice that none of them appeared either apologetic or embarrassed about missing the most important part of the demonstration.

In time, I observed that arriving late for, or failing to turn up at, events is common in activist circles, despite the time and effort invested in campaigns. Possibly the most extreme example was a Westminster protest that had been planned for World Mental Health Day when I was the only person present. However, thinking more about the RMH demonstration, I realised that many of the obstacles interlocutors confronted that day were not fully under their control. Thus, what stands out from the inconsistency of interlocutors' engagement in activism is not so much a lack of political will as the overwhelming personal and structural constraints they contend with. Interlocutors complain about having to drop

out of campaigns often, whether temporarily or permanently. Sometimes this is because of a personal crisis, though frequently it is due to the grind and unpredictability of daily life. Many activists are worn down by everyday pressures such as shortages of money and problems with accommodation and services. [328] Austin, for example, lamented that, "Between going to the shops and searching for bargain clothes, filling out benefits forms, I sometimes just can't do it". Other common obstacles include the side-effects of medication and lack of (or anxiety about taking) public transport.[329] I came to conclude that some interlocutors seem to experience a kind of 'stuckness'—by which I mean they are unable, physically and emotionally to move through London, or complete tasks as and when they choose, or need to; this often being due to events beyond their control. This is evidenced by a remark Bryan made one day. Bryan does not feel that he is in control of his life;

> You are dependent on the whims of others – you don't have agency in your life, and it's virtually impossible to make long-term decisions, because other people simply cause chaos in my life. For example, a caretaker of a local church lets me sleep on a porch when I can't find other accommodation. But he has gone on holiday and forgot to tell the stand-in caretaker… so now I have to move suddenly. I have bags of gear to shift, and I can't think straight. You are on this vast unseen chessboard where everything is related to everything else. And if you make one small (wrong) move, everything can fall apart. It's like keeping a whole load of plates spinning simultaneously, and nobody, except other mad people will help (Bryan, 2019).

By the same token, Will and Julie argued that being on benefits makes all the difference as it means they have a lot more time and energy than other activists for volunteering and activism. Yet, even so, Will conceded that he is sometimes force him to withdraw from campaigning when his benefits payments are cut or delayed.

Several interlocutors made the case that mental-health activism is more demanding emotionally than other forms of protest. For example, Lissa stated that, "the demands are

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[328] Such responses are similar to the ways in which certain homeless people in Canterbury who lack spatially fixed points such as homes or workplaces, are unable to adhere to the rhythms of a local drop-in centre or other official appointments because "time is dictated by bodies rather than by watches or clocks" (Auger 2017; 49).

[329] As Johnson-Hanks notes, there is less predictability in life than is often depicted; even "common things such as taking buses, (or) receiving pay checks elude standardisation" (2005; 367)

more, the risks and dangers of mental health activism are higher than other activisms...It takes a lot out of you, but you might change things for the better". Similarly, Julie complained "We're just not privileged or energetic like XR [Extinction Rebellion]".[330] Julie considers, as do many others, that her contribution to activism is diminished by her poor mental health. She described being completely incapacitated by 'episodes', when 'everything seems to spiral out of control'. Similarly, Mike observed that, "We're just struggling to keep our heads above water. I know many activists who give up because they just don't have the time or headspace to do it... They're just focusing on surviving" (Mike, 2019). Beyond this, the world of mental-health politics is recognised as unpredictable, making it difficult to plan and coordinate campaigns. As one very experienced activist, Dorotea, explained, "Everything can change with mental health activism… things can happen and change quickly. You get used to speed… the not knowing. You never know what's around the corner". Then there is the fact that activists confront a well-established and extremely powerful institutional structure and a set of scientific norms that have long been embedded in Euromerican medical culture and practice; moreover, they have seen little change, despite their efforts. Several activists emphasised just how emotionally draining it can be when coping with endless disappointment and obstruction.

Yet, despite the difficulty of keeping up with activism, the emotional toll seems to be accepted as an unavoidable cost of working for the greater good. Acknowledging that life is precarious and involves multiple pressures beyond their control, activists have become accustomed to and tolerant of sporadic and tardy attendance at political events and have low expectations of individual contributions. They talk often about "bearing with" others and continually adapt their campaigns, responding not just to unexpected circumstances and developments, but also to what Krøijer describes as, 'the energy of the day' (2015; 134).[331] Pondering on this pattern, I wrote in my fieldnotes, 'This is quite a typical, but useful lesson I'm learning. It's actually quite nice to be around people who don't necessarily hold you to things, expect things from you and respect the need to cancel according to how you feel in the moment' (Field diary, October 2018). Alexa echoed the

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[330] A 'non-violence, civil disobedience' Climate Justice movement which has emerged over the past five years, congregating particularly around large cities such as London and Edinburgh.
[331] Interlocutors were often late or would not turn up at all to meet me, for example, the title of this section is a text from Nadia who, on our fourth re-arrangement, sent a text asking me to "bear with" her, as she navigated unpredictable bouts of ill-health.

same sentiment when she observed that she and other 'mad' people have found a way to turn their struggles into a positive attribute;

> The Coronavirus pandemic is how mad people have had to live all along; the complete collapse of all certainties of our lives as we knew them. Acute uncertainty, which albeit painful and anxiety provoking, has always helped us to cultivate humility and open-mindedness (Alexa, 2021).

Disclosive freedom

The more I participated in activism the more I came to appreciate that "bearing with" others involves an unquestioning acceptance of tardiness and absences, as well as random and inexplicable, and sometimes worrying, conduct, some of which disrupted the wider group. "Bearing with" someone is about *more* than having patience with them; rather, exercising particular capabilities such as tolerance and attunement. I see this highly accommodating ethos as very similar to 'disclosive freedom' Zigon (2018). For Zigon, 'disclosive freedom' is a form of everyday 'relational inclusivity', in which agonists "resist being boxed in, or imposed-on, by *a priori* categories and ways of being, cultivating instead the 'freedom to *become*" (2018; 108). Zigon explains that there is neither an 'is' nor an 'ought' in agonists' way of being, and nor is a linear trajectory for political decision-making considered desirable or expected (2018; 156). In fact, any way of arriving at decisions is acceptable. Disclosive freedom, Zigon contends, "differs significantly from sovereign freedom, (self)-mastery and control" (101; 2019). 'Bearing with' someone is the exercise of the capacity of tolerance for the sake of others. And as Zigon points out, disclosive freedom is *not* a stance of 'non-participation' rather, an openness by which one lets "worlds and their inhabitants become what they may" (2019; 103). It does not simply 'happen' between people; nor is it a consequence of inaction (ibid; 111). Far from it, letting people make their own choices requires skills that must be actively cultivated. This resonates with my own field experience; the constant waiting for things to happen and the frequent changing of plans necessitated considerable understanding and patience, as well as a willingness to compromise and adapt. Recall, for example, the time that we all sat anxiously watching Nadia's brother climb onto the roof of the building we were meeting in without intervening to prevent him from falling [chapter 5]. Despite our concern for his safety, it was more important to leave him free to do what he wanted. I often witnessed activists 'letting-be' in this way. To take two examples from the RMH demonstration, this attitude is evidenced

by Julie's and Lissa's calm acceptance of the poor turnout at the poster-making session and the organisers' failure to apologise for turning up late at the event. Activists' flexibility and their ability to manage disappointment contrasts strongly with my own personal impatience and sense of frustration; I was the only person who found these incidents difficult. I suggest that the seeming chaos of activism is not necessarily as counterproductive as one might imagine; instead, it is an expression of the politics of disclosive freedom. 'Bearing with' people and cultivating disclosive freedom can make a vital contribution to healing—an idea that I explore further in the next section.

6.4 Re-configuring 'failure' and disappointment

Here, I show that even though the stated objectives of the RMH demonstration were not met, interlocutors came to regard the protest as a significant success.[332] In fact, it was soon celebrated as a major achievement both within and well beyond activist circles. I argue that this is for two reasons: first, in light of the constrained circumstances, the objectives were re-worked to be sufficiently vague that any outcome could be viewed as positive; and second, the process came to mean more to interlocutors than the results (Razsa 2015: 11). Thus, activism can be seen as a process of continual adjustment in which political objectives are kept open and flexible and expectations moderated, so that hope can be sustained even in very difficult circumstances. After the protest, activists understandings of 'failure' and 'achievement' were reframed; this being their way of avoiding a sense of failure and disappointment—emotions that have serious consequences for interlocutors (as I show in section four).[333] In this sense, re-framing the demonstration as a success afforded protection against circumstances beyond activists' control, enabling them to find ways "to go on in a world which 'wounds'" (Raschig 2016; 31).

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[332] Of course, there were those who did occasionally get frustrated and express a need to be politically moving toward something more 'concrete,' for example, Kieron once explained that he felt that the more politically active members had more rights to be part of survivor and evader organisations, as they were "doing what we're *supposed* to be doing"; constantly striving towards political achievement. However, expressions such as Kieron's were not often well received.

[333] Anthropologists tend to examine the lived experience rather than the strategic outcomes of social movements (Bonilla 2012) yet in this chapter I look at the lived experience *of* the strategic outcomes i.e., what it means to constantly reinterpret (and transform) your experiences.

Certainly, the demonstration did have some impact, since it led The Royal Society to decide against hosting government review meetings again. That MPs and NHS executives were to be prevented from using an important London venue in the future was much applauded by activists. Indeed, this outcome was awarded so much importance that it seemed to become understood as a kind of 'extension' of the original demonstration goals. In the taxi on the way home from the demonstration, Julie turned to us with a wide smile and exclaimed,

> Did you hear that the manager of The Royal Society told the meeting organisers that they will never host [name of seminar]'s meetings again? They said they had no idea what the meeting was about, but now that they do, they do not want to host the NHS execs a second time. They've cancelled any future meetings involving members of parliament or NHS representatives! They were shocked at what we had to say… I told them all about the harm and abuse the cuts would cause, and how many lives rely on continually depleting services. They listened to us!

I paused, unsure how to respond given that it seemed unlikely that barring access to a single London venue would have any impact on mental-health budgets and services. As if noticing and seeking to challenge my scepticism, Julie blurted out, That's a great success! That's one less venue in London they can hold their meetings in!". Thinking of the countless venues government and NHS officials are still able to meet in I failed to respond adequately a second time. "It will have a huge impact...If we can spread the word and then other venues might close their doors too." She continued. Then she bent down and began enthusiastically messaging fellow activists on her phone, claiming that the demonstration had been a 'huge success'.

Reflecting back on the small, nervous crowd at the protest and the sparse social media and press coverage it had attracted, I found it hard to understand how Julie could view the event so positively; it almost felt as though we had attended different events. This sensation remained with me in the following months as Julie and other RMH activists referred repeatedly to the demonstration in glowing terms. Despite the anxiety that travelling to the demonstration had invoked for many, the clash with security officials and arguments between actors, RMH activists were clear that it had all been well worth the effort. Referring to the confrontation with the security officials, Greg recalled with pride and a smile how they had batted off threats to call the police in. He was also pleased that

representatives of Psychologists Against Cuts had turned out to support them, and not the strong influence they had enjoyed on social media. Similarly, Alexa spoke with excitement about "all the aggression we faced", including "eight different attempts to kibosh the demo, starting with the huge security bloke early on yelling and trying to snatch away our banners and placards, which didn't work. It was a great win for us that everybody held together and faced them down one at a time."

As activists reminisced and debated about the demonstration, the differences of opinion and mistakes made on the day were all forgotten. It was evident that the event was 'something' well worth talking about; in fact, it soon became one of the most talked about activist events of that year. It seemed that for some interlocutors simply having demonstrated was accomplishment enough, regardless of the outcome. [334] This resonates with Raschig's (2016) research with Latina women who try to heal from entrenched oppression within their community (see introduction). While Raschig asserts that, "these modes of being-together in and beyond the [healing] circle are generally not immediately legible as a form of activism, given widespread liberal expectations of more heroic political action and the conceptual detritus of democracy that gives language to activist endeavours" (2016; 31) she argues for the importance of viewing their actions as a different kind of (otherwise) politics (c.f. Jupp 2020).

As with Raschig's interlocutors, it is not always possible to discern concrete achievements from mental-health activism in the UK. However, discussing the RMH demonstration regularly over subsequent months created a sense of momentum, not just among RMH activists but also in wider mental-health circles across London. There were no discernible 'moments' when interlocutors' ideas about the demonstration were seen to shift; the change in understandings was both subtle and gradual. Due to the very limited press and social media coverage, many mental-health activists only learnt about the demonstration after it was over. Yet it came to be perceived as a huge success, to the extent that it eventually attracted the attention of activist networks well beyond the field of mental health and was reported on in disability activist papers and journals. This development enabled

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[334] It is worth referring back to chapters 2 and 4, which make the point that for interlocutors to put themselves physically in that place was not a small matter, partly because of the constant threat of sectioning or arrest.

RMH to build an online trail and 'legacy' and make connections with the broader activist movement and the wider public.[335]

In chapters 2 and 4 I reasoned that mental-health activists often struggle to be noticed and taken seriously by health and social-welfare professionals. I suggest that the demonstration also played a constructive role in this regard. It gave RMH activists the sense that they were moving toward a different trajectory, one in which they are listened to and respected. For example, even though she had left the demonstration early because of protestors' reluctance to storm the seminar, sometime later Lissa emailed RMH activists, declaring excitedly that "We are now a cause celebre in some circles". She praised the event as having conveyed a powerful sense of collective unity– asserting that 'everybody held together'. This sense of uncritical optimism is often applied to mental-health activism more generally. For instance, Julie has high ambitions for these campaigns, and appears pleased with all such endeavours, regardless of their effectiveness.[336] I concluded that celebrating all political actions as a success is one way in which interlocutors like Julie are able to keep going, even when their achievements are extremely modest. In other words, my analysis concurs with Raschig's proposition that activism "makes an amenable preamble to a life" (Raschig; 2016, 146).

Moments of transformation

Taking Zigon's (2018) argument one step further, I suggest here that rather than thinking of activists' political struggles as ineffective, responding to uncertainty and a myriad of structural and personal constraints may produce 'conditions of possibility' (Anderson 2009: 78). Adjusting to the challenges thrown up by the demonstration created possibilities for relationships to be formed and reworked, enabling activists to enact mutuality and gain a sense of 'belonging'. As well, activists developed the sense that they were moulding their own destiny, a process that facilitated self-realisation and personal transformation.

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[335] RMH were supported by journalists from activist groups Recovery Binned and Disabled People against Cuts
[336] Often, she suggests that we invite a particular MP to meetings to help us strategize for a particular campaign. Tracking down their email address and writing to their secretary, she would become elated when she received a response, even when it was framed in non-committal terms, for example telling her to 'send over the details so '[name of MP]' knows where to go if he/she can make it'. She did not seem deterred even when the MP in question did not turn up.

By around halfway into the demonstration, only ten activists remained, most unable to withstand the cold and rain. A protestor unknown to RMH (Greg) began circling around the small gathering. Holding a microphone, he shouted, "Come on, let's 'speak up' and 'speak out'". The activists seemed nervous and would not look directly at him. Eventually, Alexa turned to Will, and asked him if he would like to speak. Will glanced around anxiously and stammered, "I wasn't planning on it...I don't know if I should. I don't know what to say. There are probably other people here who are better qualified to speak". Noting his reticence, the group encouraged him to speak out, though Greg then added, "There's no pressure". Eventually Will reluctantly took the microphone. Trembling violently with his hands shaking, he stood beside the portable speaker. In a gesture of support, Alexa and Greg moved to stand close to him. Mumbling and looking at his feet, Will began recounting his experiences in hospital (see chapter 4 for details), explaining that while he was being restrained a nurse had punched him. He talked about the violence perpetrated by staff against patients—pointing out that the general assumption is that patients, not staff, are the offenders. As he spoke, his confidence grew and he began to relax, his face lifting. He told us that he had "never experienced stigma worse than from mental health professionals".

While Will was speaking, Lissa joined—having been in the spending review meeting up to this point. Looking shocked, she stammered, "It's awful in there". "They are saying all sorts of crap. They want to increase digital therapies and replace day centres with apps". Then, she shouted loudly to the crowd, "Come! Let's storm the building!" and without waiting for a response, ran back inside. None of us moved to follow her. Some looked sheepishly at their feet. Julie took up the microphone and, taking a deep breath, began to explain that for the past four years she had been taking Sodium valproate, which, in conjunction with her other antipsychotic medications, makes her doubly incontinent. She complained not only that this is both expensive and embarrassing for her, but that her psychiatrist had claimed this drug regime was the only one available, when she had discovered a different drug combination that does not have these side effects.[337] After speaking, Julie seemed spent and sat down on some steps to rest, holding up a sign with the slogan, 'Arbeit Macht Frei' ('Work will set you free'), which the Nazis embossed on the Auschwitz gates during the Second World War. A passer-by confronted Julie. Explaining that she is Jewish, she asked Julie why she was displaying such an offensive message and said she should take the sign down, as it gave the impression that the protest was a pro-Nazi rally. Julie disagreed, replying that,

> The way the government are forcing people in mental distress back to work when they're not ready is genocide… it kills them and is a form of social cleansing. 'Arbeit Macht Frei' is aimed at the attendees and organisers of the seminar, because they are trying to annihilate us. The public health message is that work is good for us and will emancipate us from mental illness. As someone who would have been sent to the gas chambers of Nazi Germany on grounds of mental 'illness', I call that genocide. I own this issue as well.

The argument continued and the woman finally walked off in anger. Someone whispered nervously, "Will she call the police?" Julie responded by saying that the woman's intervention was in fact a move by the review-meeting organisers to, "halt the demo and have us taken away – on the basis of political correctness and inciting discrimination".

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[337] The alternative regime is more costly, and Julie presumes that this was why the psychiatrist will not change her prescription. Activists often gauge how well Julie is through the strength of her odour—concerned that when it is strong, she is either neglecting herself, or short of money. She is not permitted to receive incontinence pads on prescription, so buys them at £12 a packet- sometimes using one packet a day. She has to take her bedding to the laundry and replace mattresses regularly. Coming off the medication is not an option as this would cause her to have serious withdrawal symptoms.

Even though Julie was smiling as she said this, she seemed anxious. Then, a smartly dressed man in a suit approached and asked us why we were filming him, demanding that we delete the footage. Greg managed to persuade him that we should be allowed to keep it, and the crowd cheered.

There were more small moments of triumph later that day. After the demonstration was over, we gathered at my house for a debriefing, during which, Will, Alexa and Steve shared their experiences of hospitalisation. Pushing the laptop to one side, Greg stood up and pulled his trouser leg aside to show us a long, angry scar. "I got it from jumping off a bridge." He paused. "When I tried to…" "When you tried to what?" prompted Julie. "…When I tried to top myself in 2005". I was not surprised that Julie urged Greg to speak. Suicide and suicide 'ideation' are common in activist circles and speaking openly about the topic is routine (see chapter 1). Whilst pulling his trousers back down, Greg tripped over a table leg and we laughed. He declared "I'm having so much fun". Then, glancing at his watch, he sighed and exclaimed,

> I'm supposed to be going to group therapy tonight. I need to attend to prove to my workplace that I am trying to 'get better'. I've been told to attend six sessions….They insisted on it. But this right now is so much better than group therapy. I should cancel it. All the other people in the group, they're all stiff. No one chats outside of sessions, or even smiles... but I feel like I've known you all for years. I can tell you stuff.

After this discussion Greg became a regular attendee at protests and meetings, the demonstration having consolidated his relationships with activists.

In this section I have shown that mental-health activism enables multiple possibilities; each action constituting a potential becoming. The demonstration changed interlocutors' horizons, presenting them with new opportunities and a sense of hope. For example, Greg discovered a new community of people that he identified with more—and experienced as more therapeutic—than his therapy group. Similarly, the demonstration turned out to be extremely significant for Will, not least because he found the courage to talk about his painful experiences of hospitalisation in spite of his fear of speaking in public. Reflecting on the speech, he said it had been extremely empowering and made him feel more important and useful than he had in a long time. Having been on disability benefits and

living in supported accommodation for most of his adult life, Will had felt neither worthy nor fulfilled. Participating in the demonstration sparked in him a long-term commitment to political activism, which, he explained, gave him a sense of purpose and community. Julie described how expressing in public the unjustness of her situation, standing up for her beliefs around workfare and genocide, and challenging the views of a member of public, had made her feel triumphant – and had given her a sense of achievement. Likewise, the placard-making session reminded Lissa and Julie of their past, when they were happier and less caught up in the 'revolving door' syndrome. These moments of personal transformation and mutuality experienced through protest opened up other futures, allowing activists to 'be differently'.

6.5 "Power makes us sick": the personal repercussions of politics

"Despite the wins, the war continues" (Zigon 2018; 118)

In this final section I make clear that political activism around mental health often has significant personal repercussions for those involved and comes at particularly high emotional and material cost. In the weeks following the demonstration, interlocutors revealed that they had confronted numerous challenges, many taking a long time to recover. I therefore suggest that, in the context of overwhelming structural and personal barriers, the emotional and psychological toil of campaigning on mental-health issues is such that it can make people sick.

Figure 9 Recovering post-demo

Towards the end of the demonstration, Dave, who I had not met before, approached us and, explaining that he was 'flagging' and needed a break, asked if anyone would care to join him for a cup of tea. I accompanied him to a local café, and he told me that he was stuck in a 'catch 22' situation. His wife had been diagnosed with cancer. Following her death, he had fallen into a deep depression and had just undergone an ESA. [338] Commenting that waiting for the results is "really very stressful", he had joined the demonstration partly as a distraction. He also hoped that connecting with others who were also struggling with poor mental health would help him combat loneliness and give him a sense of affinity and belonging. However, the demonstration had only exacerbated his sense of desolation. Totally absorbed in the task at hand, the other protestors seemed reluctant to talk to him. Further, despite feeling unwell, he felt under pressure to remain there due to the small numbers and torrential rain. Looking dejected, he explained that even though he felt that he was letting others down, he no longer had the energy to remain standing in the cold and really needed to go home.

While Dave was talking, Julie called me. Sounding irritated, she asked, "Where have you gone? I need your help". As I arrived back at The Royal Society, Bryan was helping Julie load the soggy banners into the back of a large taxi.[339] It was after midday and most of the protestors had left; those who remained were wet-through and looked exhausted. The delegates and passers-by had all departed and the security officials had gone back into the building, leaving us alone. We agreed on the need to regroup for a debriefing and nodding at the taxi, Julie said "We'll pay for it using the last of our donation money". Then, suddenly, Lissa rushed out of the building and close to tears, yelled furiously that she had been on her own throughout the meeting. Reminding us that the meeting was where all the important decisions were being made and complaining about having been left unsupported, she asked why none of us had joined her. She did not wait for a response, but ran off, announcing that she was going home.

Will, Greg, Julie and I took a taxi to my place, and Alexa and Steve went on public transport. Squeezed next to me in the back of the cab, Greg's breathing seemed laboured and erratic, and Julie asked if he was alright. He replied, wheezily, "I'm having a panic

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[338] ESA is allocated to those who cannot work due to illness.
[339] Far outnumbering the number of protestors, most of the banners had been propped up against a wall throughout the event, their paint leaking into the gutter.

attack...I just received a response to an email about my sick leave at work. They are refuting my phased transition back into work. I've been signed off six months now and they want me to come straight back". This email was a stark reminder of the stressful interruptions interlocutors regularly experience due to workfare. On arrival, we made ourselves comfortable in my sitting room, apart from Will, who paced back and forth. When I asked him if he would like to sit down, he said he was agitated by the day's activities and 'could not stop' moving. Greg asked to borrow my laptop and sat to one side, re-reading his email and jiggling his knees nervously. He explained that he preferred to read the message from work whilst in company rather than when alone. Meanwhile, Julie, sitting under a duvet, was looking shell-shocked and her face was grey. When I placed a plate of biscuits in front of her, she glanced at me gratefully. Then Steve and Alexa arrived. Sitting close together, they were speaking rapidly to each other about the protest and how it might have been handled better. Steve listed the things that had gone wrong, foremost of which was everyone arriving late. Sighing in frustration, he announced, "We're gonna have to get over always being late". Will responded by exhaling loudly and observing that we were all exhausted and deserved a break. A discussion ensued, in which Steve argued that there was no time for rest and that if we did not immediately record what had happened, vital lessons would be forgotten and lost forever. The intensity of Steve's desire to reflect on the morning's activities was evident and for a while we tried to keep up with his brainstorming, although there was some tension in the room. Julie tried to contribute by calling out suggestions from underneath the duvet. But Steve told her that if she wanted to be involved, she should do it properly and sit with everyone else. It was clear that Julie did not have enough energy to move, and the exchange fizzled out. Later, as we made to leave, Greg thanked us for 'taking him out of himself'. But when Alexa asked him if he was OK, he replied, 'not really'. He invited us to his birthday party, which was to be in a few weeks' time. We congratulated each other on the demonstration, wished everyone a well-deserved night's sleep and agreed to meet up again soon. I wondered why we had congratulated each other—whether it was to infer 'well done for getting through it', or 'for trying your best'. It felt as though something momentous had happened, but I was unsure what that was.

When I awoke the next morning, I discovered texts and missed calls from Greg and Julie. They had called well after midnight, and I was concerned why they were trying to reach me so late. Greg texted again, saying that Julie was not answering her phone and asking if she was alright. I knew that in the past, sleep deprivation had caused her to 'spiral',

which she describes as feeling as though 'everything is spinning out of control' and being unsure when she might 'come back'. Given that she had not slept properly in the days before the demonstration, I assumed that she was simply resting. However, I learned later that unable to sleep, she too had been trying to contact me. Having been up all night, Steve also began sending me frantic messages, from around 3am. He asked me to contact the man who filmed the demonstration and get him to give me the footage so I could post it on social media. "Time is of the essence" he wrote, "we need to get the footage out there". He added, "But don't let him come to your house or let him know where you live. Trust no-one". Greg also copied me into a heated email exchange he was having with his workplace about the dispute over his sick leave. He asked for my help in writing a response and I did my best to steer the discussion in a more constructive direction.

Following this flurry of activity, I did not hear again from RMH activists for almost a month. Since it was highly unusual for them to go silent in this manner, I began to worry that something might be wrong. The last communication from Lissa had been an email to our RMH google group entitled, "Where were you all?" In it, she reiterated her anger at being left alone at the demonstration and explained that she would be recuperating at home, isolating herself from others and ignoring social media. However, a few days later, she emailed again to say that she was 'beating herself up' for being angry, and 'messing it all up' and acknowledged that it had been her decision to enter the building on her own. These comments illustrate just how strongly interlocutors feel about fulfilling their responsibilities towards others. They also show that Lissa acted with disclosive freedom, as others had when they ignored her pleas to assist her in disrupting the meeting.

We finally met again some weeks later, at Greg's fortieth birthday party. Julie explained her long silence by outlining how much the demonstration had impacted her. Preparing for and participating in the protest had taken all her energy and when it was over, she could not even manage to read her emails. When she got home on the evening of the demonstration, she slept for a full twenty-four hours. Then, exhausted and unable to do anything, she 'hung about' the house in pyjamas for a whole week.[340] Steve also fell ill after the demonstration. He was very agitated and unable to sleep, so took sleeping tablets. Despite trying for a long time to wean himself off them, he also increased the dose of anti-psychotic drugs that he had been prescribed. Recovering at home and unable to

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[340] During this time, her teenage son did the cleaning and cooked their meals.

go out, he too had not seen anyone in weeks. Similarly, Janet decided to cancel all the 'SolidariTEA' film screening nights to prevent fellow activists from experiencing 'burn-out'. No one had heard from Lissa since her email, and Julie lamented that she had lost a close confidant, adding that 'This is what tends to happen after a demo'.

Even though the demonstration was viewed enthusiastically by all involved, it had clearly taken huge amounts of energy for interlocutors to do the planning and make the arrangements, as well as to show up in a public place, tell their stories, and travel home again. Triumphs, such as standing up to a member of public (or indeed, standing up in public) came at a price; the event had adverse affective and somatic impacts on all involved and these impacts persisted for weeks, beginning prior to the protest and lasting long after it was over. The symptoms included panic attacks, nausea, exhaustion, relapses of distress, having to take long-avoided meds, as well as feeling under pressure to protest. As Julie lamented in the week after the demonstration, "my stress mocks me in the mirror". From this evidence, I maintain that interlocutors experience politics in intensely physical and embodied ways, making significant personal sacrifices for political ends.

6.6 Chapter conclusion

In this chapter, I argued for the importance of understanding activists' political approaches as intentionally indeterminate; their refusal to ascribe to particular ideologies or goals being part of an 'otherwise' politics. It is not that activists *do not have* any goals; it is more that some goals are kept intentionally vague, and others change in the process of enacting politics. I illustrated this argument by analysing an RMH demonstration held in 2018. I used this example because the protest has many parallels with other activist campaigns and events. I outlined RMH's motives for initiating the protest and showed how, despite careful attempts to work to a specific plan, the outcome did not reflect their original intent. I suggested that this was not just because politics are inherently uncertain, nor because often things do not go to plan. More to the point, the seeming lack of fit between intentions and outcomes is part of a politics of 'disclosive freedom', or an acceptance of individual distinctiveness and the right to self-determination, which can change the orientation and results of political action. Among activists, disclosive freedom facilitates individual autonomy and allows individuals to participate in activist networks and events on their own terms. By executing disclosive freedom, activists detach themselves from the burden of classification, and foreground agency and self-governance over identifiable political goals,

manifestos or objectives. I demonstrated that disclosive freedom also forms part of how activists respond to situations, not only avoiding failure and disappointment, but also enabling activists to sustain multiple interpretations and meanings of success.

I demonstrated how structural conditions, such as fear of intervention, transport issues and pharmaceutical side-effects, become entangled in interlocutor's everyday lives, impeding their attempts to engage in political action. In this sense, engagement in politics has the potential to 'make people sick'. Consequently, activists ask that their peers to patiently "bear with" them, including sometimes by suspending action. I showed that what 'matters' in terms of political action changes according to individual priorities, abilities, and energies. Thus, even though the sixty or so carefully prepared signs were abandoned during the RMH demonstration, soaked by the rain and leaking their messages into the gutter, they remained a symbol of commitment and endurance. I argued that among activists the constant changing and circulation of intentions contributes to the imagining of different futures—these being in the form of 'unfoldings' and 'assents' rather than certain 'choices' and directionalities (Johnson-Hanks 2005; 363). As the meaning of the RMH demonstration changed over time—on the day, as well as in the months succeeding it— 'new' and different selves emerged in the indeterminate space it had created; this, in turn enabling possibilities for healing. Stories of success spread throughout the activist movement, transforming memories and legacies. Activists became triumphant through small, personal changes and intangible moments; (re)producing and (re)imagining themselves in spite of seeming failure.

Thus, indeterminacy can be seen as a modality of doing politics that is purposefully 'in between'. It is the suspension of political goals and the "negation of a clear path toward the future" (Sanchez 2021, pers comm.). This does not mean that activists do not have *any* ideas about or enactments of the future; it is just that they reject overarching, coherent narratives. I maintain that this is because for activists, politics is always changing. I expand the notion of otherwise politics, which proposes that the possibility of activists living the change they wish to see is precluded by structural constraints, by showing that interlocutors *intentionally suspend* the prefiguration of exact futures. In this way, by living 'outside' existing structures and rules, they try to create something different. For activists, changing their own worlds by reframing the uncertainty brought about by structural violence helps create hope and sustain relationships. Indeterminacy is a mode of being in which actors figure out other worlds and other selves.

VII. Conclusion: Healing Through Indeterminacy

In this thesis I have examined the diverse but interconnected individual, collective and embodied experiences of TAU and mental-health activism. Here, I summarise my argument, bring together my key findings and discuss how my work contributes to anthropological scholarship and other disciplines and fields of study. I discuss the findings in two parts, the first of which[341] addresses interlocutors' experiences of and responses to TAU and social-welfare provision and the second, [342] activists' efforts to build indeterminate worlds of healing. I go on to outline how my work contributes to the literature[343] before briefly considering the implications of my research for UK NHS health services.[344] I end by suggesting how activists can help re-imagine mental healthcare.

VII (i) "We're not 'mad': we're angry"

One afternoon I stopped by a mental health service-user café for a cup of tea, where I found Bryan in a state of distress- pacing around and sighing agitatedly. I asked what was bothering him. Frowning angrily, he replied, "When you are mad, without a job, people offer things to you that you don't want". Surprised, I asked him to clarify. "Mad people have to learn to refuse" he said, staring ahead. People often try to give Bryan gifts, or 'help' him out. I suspect this is partly because he has the appearance of a rough sleeper—weathered skin, unkempt hair, and carries an oversized backpack that contains all of his belongings. He explained that he feels burdened by these gifts and offers of help. Before I arrived in the café a woman had approached him. Having heard his Irish accent, and trying to be kind, she gave him a book on Irish history she had just finished, explaining that she thought he might like it. Bryan felt obliged to accept the book and to start reading it as she was sitting nearby. Bryan had been feeling overwhelmed and had gone to the café to clear his head and plan the coming few days, but having his peace disrupted and sensing an

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[341] Section VII(i), which mainly covers the findings from chapters 2 and 3.
[342] Section VII(ii), which focuses on chapters 4-6.
[343] Section VII(iii)
[344] Section VII (iv)

obligation to accept a gift he did not want, he became agitated and disoriented. He said he was 'beating himself up' for not being able to say 'no' to a stranger. Although the woman's intentions were good, she had made assumptions about his needs. This incident clearly depicts the challenges activists struggle with, in a world where they desire to be 'let be' (though not necessarily alone), and yet are constantly being interfered with. That Bryan felt compelled to gratefully accept a gift he did not want, took attention away from his actual needs and increased his feelings of distress. Many of the activists I worked with have spent their lives accepting, or worse, being forced to accept, treatments they do not want, this prejudicing their attempts to heal.

Clearly mental healthcare in the UK has supported countless individuals in a myriad of ways, greatly lessening the suffering of many. However, I show that for some, 'TAU' can be a source of iatrogenesis. In the case of activists, this may, in part, reflect the inability of medical interventions to counter or avoid reproducing structural violence, or social constraints. Among activists, long-term, often acute, mental distress is frequently compounded by livelihood shortfalls, insecure accommodation, and disrupted family ties. In chapters 2 and 3 I outlined the enormous impact such structural and personal circumstances, operating together, have on activists and their lives more generally. Evidently mental-health interventions have only limited capacity to combat such conditions.

I showed that within NHS mental-health provision, activists experience a fundamental misalignment of their own realties and clinical frameworks, which heighten, rather than alleviate, their problems. There is an epistemic and phenomenological dissonance between clinicians' explanatory models and the holistic approach advocated by activists. Activists dispute the validity of the biomedical framework, with its attention to intrapsychic processes, linear treatment pathways and productivity outcomes (Calabrese et al. 2011). They draw attention to the tendency of biomedical models to treat individual pathology in isolation from the social, political and economic causes of mental distress and reject the notion of mental 'illness', focusing instead on poverty, isolation, work stress etc. For activists, clinical understandings and modes of addressing mental illness are not just different paradigms, but are denials of their worlds.

I used the term mental 'distress' in place of 'mental illness' to reflect activists' rejection of pathology as well as their own use of the term. I made clear that despite successive efforts

by governments to improve the efficacy and efficiency of NHS services, the legal and policy landscape of mental healthcare does not reflect interlocutors' lived experiences of 'TAU'. For example, whilst recent NHS rhetoric champions 'partnership', patient 'empowerment', 'patient-centeredness' and 'autonomy', activists regard mental healthcare as a site of relational failure. Although service providers may endeavour to invite collaborative healthcare through 'co-production' and similar ideologies, Jupp argues, these aims are rarely realised in practice, such discourses offering false hope, which can "re-direct attention and close down other possibilities" (2021; 977). In critiquing TAU, activists point to the asymmetrical power dynamics in the patient/clinician dyad and highlight their experiences of mental healthcare as authoritative and disempowering. Clinical encounters leave activists feeling bereft. Lacking control and having their personal histories and experiences ignored, the aftermath of such encounters have been greatly aggravated in recent years by efficiency drives, cuts and wider biomedical service failings. Activists also mistrust the notion of recovery employed in many NHS treatment models; indeed, they question whether recovery is possible or even desirable. They regard efficiency drives and formulaic treatment pathways as serving bureaucratic rather than therapeutic ends, also taking exception to interventions that prioritise short-term, measurable outcomes and discount their longer-term, existential, anxieties. The fact that social welfare nets do not necessarily offer the support needed is yet another source of distress. With welfare benefits tied to medical diagnoses, refusing treatment following a diagnosis can mean a person's benefits are reduced, even stopped, thereby risking loss of both livelihood and accommodation. The dependence of welfare benefits on compliance with prescribed treatment regimens creates conflict for interlocutors who often feel this gives them no choice other than to use services they consider more harmful than beneficial. Moreover, often the burdensome bureaucratic procedures involved in seeking support fail to reflect activists' needs. However, among their many grievances, activists' greatest probable concern is the use of compulsion in mental healthcare—as, for example, when patients are hospitalised or medicated by force.

Thus, from this I conclude that activists are caught between conflicting subjectivities. Acutely aware of their positionality, they strive to assert both their competence and their right to contribute to their own therapy where they can, whilst also calling out injustices and advocating for service reform. More apparently benign clinical appointments become complex negotiations, with activists often resisting and preventing healthcare from taking place. At the same time, a mental-health diagnosis means they are designated by

clinicians as vulnerably dependent and incapacitated, with the result that they are given little (or no) say in their treatment. Activists regard this to be an intentional act of silencing, or hermeneutical injustice. The conflicted landscape of mental healthcare, in which independence and agency are aspired to, but are at once shattered by enforced interventions, leaves activists feeling powerless to define their needs or shape their healthcare. In this way, activists' engagement with formal services corrodes their sense of independence, deprives them of personal liberty and ultimately, undermines their healing.

VII (ii) Developing 'a culture of madness'

In the second part of the thesis, I have explored how activists conceptualise and manage mental distress, as well as the part mental-health activism plays in their lives. As noted, activists refute not only the structural inequalities entrenched within capitalist society, but also the biomedical model of mental health. Among activists, healing is not about clinical procedures implemented by professionals; nor do they accept the temporal logic of biomedical treatment, with its assumption of linear progress from sickness to health. Activists' efforts to develop their own approach to healing has far more to do with transforming their social and political environments than treating sickness. That said, I also found that activists avoid generating their own definition of healing, for to do so would create the same pitfalls as in biomedical practice–wherein persons who do not, or will not, adhere to formal diagnoses and treatments are excluded from both support and the possibility of healing. Instead, mental-health activists have a very broad understanding of healing. They perceive it to be a complex, dynamic, polythetic process, with many possible manifestations and outcomes—a process that also involves prefiguring and imagining a different way of living alongside mental distress.

Zigon's concept of 'worldbuilding' is the most apposite framing of activists' mode of healing, since it conveys the idea that activists found alternative 'social and political imaginaries' (Zigon 2017) and alternative forms of political citizenship. Worldbuilding is about actors living the changes they wish to see in ways that are available to them - recognising that the ways open to activists are constrained, due to the many personal and structural challenges they confront. For example, simply by refusing to use the language of illness and rejecting formal diagnoses, activists undermine the epistemic authority of service providers and prefigure a world in which individual pathology has no place. Rather

than curing illness, or working towards an immutable state of recovery, activists' approach to healing means understanding and utilising distress in different ways; creating a more equitable world, and living independently, without intrusion from others. To this end, activists create spaces for experimental ways of being in which flexibility is a reflexive response to situations. Actors encourage one another to make their own choices, their needs being neither assumed nor predicted. These spaces are forged through relational practices that centre on letting-be, or "bearing with", others—an ethos akin to Zigon's (2018) concept of 'disclosive freedom'. In practical terms, letting-be, or bearing with, allows actors to re-construct relationships and re-configure lives by both 'being' and 'becoming' together with fellow activists. 'Bearing with' people is about exercising patience, however challenging this may be. Thus, activist spaces become 'guarding and holding' environments (Johnson 2019; Jupp 2022). The permissiveness of activists' relational practices means there are no restrictions on who takes part in activist events and networks or how they participate. It is common for actors to remain silent, stare, moan, shout and/or shuffle about in gatherings; these acts reconfigure 'sickness' as merely a normal and necessary part of everyday life.

Mental health activist networks have inhabited London for decades. I engaged the concept of mutuality to convey the social complexity that underpins the intersubjective experiences that shape relationships and create affinity and mutual feeling among peers. Mutuality is useful in depicting the ways in which activists support one another, suffusing their daily lives and disrupting the norms and asymmetries prevalent in conventional professional models of caring. Through mutuality, social, material, and emotional resources circulate among activists, helping people feel part of something 'bigger' than themselves, something that extends beyond singular relationships. Mutuality is about being closely attuned to others, as revealed in the embodied ways in which activists listen to and hold space for their peers. Interlocutors listen without restraint to fellow activists (re)telling stories of adversity and distress. Listeners hold steady to the principle of non-intervention, not expecting coherence and allowing their peers to 'go crazy and come out the other side' without interfering. This kind of listening permits many views to be expressed, including those that conflict. Listening enables multiple understandings of distress to be presented, attended to and accepted. It allows activists to innovate different ways of alleviating distress. For example, activists stand in front of crowds, conceivably growing in confidence, sharing experiences (spoken and embodied) that otherwise would likely remain secret. Activists find reassurance in recognising their own feelings and

experiences in the feelings and experiences of others. Unquestioning acceptance of personal narratives also confers on narrators a sense of their own legitimacy. These features of mutuality—attunement, compassion, acceptance and legitimacy—are vital for healing. Legitimacy is especially important for those struggling with mental distress because they are so seldom listened to, and their perspectives are so often discounted—this resonating with Andy's plea (see prologue) that he be thought of as more than an 'ill subject'.

There is also another attribute of mutuality. Activists' healing worlds require collective effort, responsibility and support for fellow activists in crisis being distributed and negotiated between people cooperatively. All actors play a part in the healing of both self and others, interrelated support being vital to sustaining activists' lives; replacing ruptured in kin relations caused by mental distress and other adversities. In activists' worlds, care 'giving' and 'receiving' are not opposing subjectivities. Close attention is given to equivalence in caregiving and care-receiving and inhabiting particular carer/receiver roles is avoided, thereby orienting toward what I call 'balance'. Moreover, activist compassion knows few bounds; trust and acceptance are extended unconditionally, sometimes to total strangers. There is also an important spatial element to mutuality. Activists' spatial practices are itinerant and fluid; activist networks occupy a wide range of locations that are dispersed throughout London and change daily. Through embodied practices such as attunement, listening, bearing with and balance, activists transmit healing across *any* location.

Nonetheless, despite the many generative, transformative features of activist mutuality, it is shaped as much by contestation and precarity as it is by attunement and 'bearing with' one another. For one thing, the acts of intensive support embedded within mutuality are not without struggle and may exact a high emotional price. Care giving and care receiving are intimately interwoven, so that actors can become enmeshed in other people's distress, sometimes at the expense of their own health. Sustained support can generate existential anxiety, insecurity, and exhaustion, especially when the suffering of another mirrors one's own. Many individuals have limited capacity to act on behalf of their peers. Moreover, when the state intervenes in subjects' lives, this can disrupt activists' careful attempts to maintain 'balance'; the generalised exchange of support within the collective is disturbed, creating struggle between people and in the community.

A final key finding is that both political and therapeutic intentions are central to the world of mental-health activism. However, activists do not perceive the 'political' and the 'therapeutic' as distinct domains, so much as highly synergistic arenas of action. This means that not only are activists' modes of healing intensely political, but that when activists do politics this can be highly therapeutic. Put differently, by campaigning for and living the social conditions they 'wish to see', activists build the foundation for their healing. To the same end, mental-health activists are deeply resistant to formal means of political organisation and engagement, activism differing markedly from conventional political modes of organising in the UK. In order to highlight its distinguishing features, I describe the political dimension of mental-health activism as a form of 'otherwise' politics, the 'otherwise' (something other and different to TAU) being founded not so much on concrete political objectives as a perpetual state of indeterminacy. This conceptualisation highlights how activists are more committed to political processes than they are to outcomes. By keeping political actions and outcomes indeterminate, activists purposefully resist staking overt political claims, defining their political citizenship, or seeking tangible results. Even though their campaigns sometimes start out with very concrete objectives and manifestos and are planned in great detail, activists' aims are often extremely vague and change in the course of a day's action. In this way, actors are able to keep their horizons open and prefigure other worlds.

Activists' ability to bring about the changes they hope for is affected by the many personal and structural constraints they confront, so that their efforts to re-configure their lives and relationships require continuous adaptation to environmental and individual stresses. The suspension of clear political goals can be seen, in part, as a response to the high levels of uncertainty in their lives—or, in other words, a way of enacting politics under highly constrained conditions. Indeterminate politics permit activists to navigate the turbulent and constantly changing mental-health landscape, cuts to mental-health services, benefit sanctions, ongoing threats of eviction, treatment side-effects and other pressures of daily life. Yet, mental-health activism also takes a toll, the emotional toil and energy of campaigns sometimes exacerbating sickness and inducing distress, as indicated by incontinence, exhaustion and panic attacks. Further, the absence of leadership and agendas in activist events can render activists open to criticism from those who cannot grasp that goals are continually in the process of formation.

The future for activists may appear opaque to outsiders, and their political activity unproductive. Nonetheless, there is also great freedom in indeterminacy; as Deleuze (1995) suggests, the power of indeterminate worlds lies precisely in their lack of a model. By not worrying about having to define themselves, or achieve tricky objectives, activists maintain a state in which political resolution is never the sole purpose. For example, in chapter 6 I have shown that what may seemingly appear as a political 'failure' can be experienced by activists as a success; these successes emerging as activists respond to external events, changing needs and personal circumstances. Indeterminacy propagates a personally and socially sustainable form of politics, one that also heals. This is because actors are less likely to be disappointed by outcomes that are malleable. Further, indeterminate political processes allow for the re-evaluation and reorientation of individual and collective objectives. As a result, by not foreclosing desired outcomes, indeterminacy contributes to the maintenance of endurance, as well as hope. It does so by ensuring that multiple possibilities are maintained throughout political action- helping to keep as many worlds open as possible. In this sense, indeterminate politics enables activists to overcome and even embrace 'failure'.

In indeterminate worlds, the content and form of activist gatherings entails the uncoupling of epistemic authority from sociality as well as from the experience of mental distress. The suspension of solutions to mental distress means that activists can experiment- shifting their understandings and forms of healing—in the face of extremely challenging conditions. Indeterminacy enables multiple possibilities, such that each political act creates a potential becoming. In the introduction to this thesis, I cited Bryan's remark that mental health activists need to develop a 'culture of madness'. I would suggest that part of this 'culture' is also about allowing oneself and others to 'become'—both as individuals, *and* as a (networked) community; emerging together in a process of collective resistance and mutual empowerment.

Thus, when Zigon (2021) poses the question, 'How is it between us?', I would also ask; what kinds of worlds can be found 'in-between' answers, when we postpone solutions? While mental-health services shut down possibility, activists' worlds are spaces that *open* possibilities—allowing imaginings and narratives in which activists can always aspire. For activists, there are no absolutes. By refusing to make their politics intelligible to others, activists maintain a state of becoming. Thus, through indeterminacy and mutuality, activists prefigure a more subjective, inclusive and tolerant approach to mental health

which encompasses plurality, alterity and autonomy; in which anyone can heal how they wish.

VII (iii) Contributions to literature and scholarship

I began this thesis by arguing that research into mental health in Euromerican contexts tends to be heavily oriented towards clinical practice and settings, which in the UK means either NHS or third sector organisations. Ethnographic studies of everyday, non-medical approaches to healing are rare in this context. This thesis contributes to the field by investigating peripatetic, multi-locational, self-led healing enacted by mental-health activists beyond the confines of institutional provision. It offers a unique account of the relationship between mental-health activist sociality, political organisation and healing in London—Service evader and similar activist networks having received very little attention thus far. In studying this topic, I make the following contributions to anthropology and wider research on mental health in the UK.

In terms of my methodological contribution, Jupp (2019; 13) comes to mind when she asks, 'Whose voices and experiences might be heard within a politics [of storytelling and listening]?' In chapter 1, I critiqued the convention in research ethics of categorising whole sets of people as 'vulnerable' on the basis of attributes such as mental illness. I argued that this disregards the variable and fluctuating subjectivities of those deemed mentally 'ill'; undermining their alterity. 'Vulnerability' is a designation which denies the capacity of persons to contribute to research. I suggested that such categorisation reproduces the processes of marginalisation, structural silencing and hermeneutical injustice that activists experience in the mental-health system—as when patients' perspectives are ignored or refuted, or even when addressed, are pushed towards coherence. In making this case my work speaks to a growing body of literature spanning Social Work, Mad Studies and Survivor research, in which activists' (and mad persons') narratives play a central part.[345] Service Survivor research groups argue that truth claims within mental health services are part of a historical injustice that needs addressing directly (c.f. Spandler and McKeown

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[345] Such moves are rapidly increasing in both academia and the public sphere alongside other efforts to decolonise education. These include the integration of Mad Studies in curricula and the involvement of service-users (referred to as 'experts in experience') in generating research evidence on mental health. Such developments serve to reduce the epistemological authority of dominant paradigmatic approaches to mental health and narrow the imbalance of power between mental-health professionals and service-users. It also demonstrates increasing acknowledgment of the validity of 'patient' experience in shaping mental healthcare.

2021). To counteract this historical injustice, I provided accounts that challenge those of 'the paper self' (see preface) by engaging directly with activists' truths.

My work also addresses important debates in the anthropology of health, medical systems and welfare. In the introduction, I questioned simplistic interpretations of structural violence, abandonment and social defeat. I went on, in chapters 3 and 5, to demonstrate how these conditions are metered out between people, the dynamics between mental-health professionals and activists being far more complex than is implied in binaries such as 'authority' versus 'resistance', or 'domination versus dependence' (Knights and Willmott 1990). I demonstrated that encounters between activist patients and clinicians are deeply entangled—these actors being both antagonistic towards and dependent on each other. For example, I showed how service-users such as Andy respond 'strategically' to assaults on their personhood (Jenkins and Carpenter-Song 2008). I examined the notion of 'wounding' (Cubellis 2019), a nuanced form of violence wherein intransigent healthcare interventions prevent activists from enacting mutuality. More important still, I argued that activists' interactions with mental-health services pervade all aspects of their lives. I framed this as the 'shadow' of biomedicine in order to highlight the entangled, affective and phenomenological intrusion of interlocutors' past experiences of mental healthcare in their current lives—also characterising this as an absent presence (Gilsenan 1996) that runs through their lives. The notion of a shadow underscores interlocutors' complex relationship with biomedicine, moving beyond a Foucauldian emphasis on governmentality and control.

In chapter 5, I argued that activists emphasise listening more than all other forms of communication and that listening is also vital to activist politics. I showed that listening is an embodied form of attention, which centres around absorbing narratives of distress without assessment or censure. This understanding has the potential to enhance sociological studies of social movements, which tend to have a very different view of activists' modes of communication. Scholars of social movements generally emphasise the act of speech as crucial to political engagement and expression. Similarly, it questions research in medical anthropology which emphasise the role of telling narratives in therapeutic process and personal transformation. I also built on the anthropological literature on care and kinship in chapter 5. First, I argued that relatedness is forged not

through 'unconditional amity', but also the struggles and strains of everyday life.[346] I suggested that discord may in fact generate a sense of security and belonging through mutual hurt, and is thus constitutive of the kind of mutuality activists enact. I implied the need for a nuanced notion of mutuality characterised not just by close 'solidarity', intersubjectivity, interdependence and sharing, but also mutual suffering and conflict. Thus, mutuality can be ambiguous, troubling distinctions between 'good' and 'bad' care that are prevalent in the literature (McKearney 2020). In accordance with Cubellis (2018) my research indicates that closer examination of the dynamics among those who attempt to disrupt care asymmetries as found in NHS practice, is critical to ensure that 'peer' support does not replicate iatrogenesis.

I pointed out in the prologue to this thesis that in research on Euromerican sociality, the unfettered expression of individual liberty is often understood as eroding collectivism and social cohesion. However, I demonstrated that among activists, mutuality is not thought to be undermined by, or compete with, individual freedoms; the collective and the individual are of equal importance, and both are incorporated in activists' relational practices. This line of reasoning contests the argument by Durkheim (1897) and others that individual liberty erodes social ties. I also suggested that mutuality is more than an exchange between individuals or dyads as it is more diffuse, being enacted through networks simultaneously, as a form of generalised exchange. By analysing mutuality in this way, I draw emphasis away from binary conceptualisations of support, contributing to understandings of collective exchange.

Finally, in chapter 6, I developed a novel way of understanding activist political organisation, thereby expanding understandings in the anthropology of politics. By combining the frameworks of 'otherwise' and 'prefigurative' politics I arrived at a theory of 'indeterminacy', arguing that for activists, indeterminacy is a vital part of intentional political engagement and organisation. Although providing incredibly useful frames for understanding political formations, concepts such as 'otherwise' and 'pre-figuration' do not fully reflect what is happening in mental-health activism. While the concept of indeterminacy is not new to the anthropology of politics, I emphasise it in a way that differs from existing conceptualisations, for example, the idea that change must manifest tangibly—does not resonate with the kind of indeterminacy deployed by activists.

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[346] This also challenges literature referred to in the introduction which frame relations in social movements as built from 'solidarity' rather than contestation.

Indeterminacy is an expression of activist agency, in which activists bring about social and political forms and processes that do not conform to existing templates. The significance of indeterminacy lies in changing the terms of power in mental healthcare; disrupting 'what counts' as reality, truth, healing, success or failure. In this way, Jupp argues (2019; non-paginated), what looks like 'localised', even 'temporary' forms of activism, in practice "makes interventions into the sphere of politics". Political change emerges through social and personal transformation; the empowerment of a population having important ramifications for the mental health movement, and mental healthcare more generally. Indeterminacy has provided a new lens with which to understand the process of 'becoming' for activists, reflecting their efforts to 'guard' and 'hold' space, rather than living out totalising plans and ideas.

VII (iv) Wider implications of the research

Despite some important recent advances in mental-health provision in the UK, there is still a long way to go. It was not my intention to evaluate mental-health services in the UK, nor is this thesis an appropriate vehicle for such a task. However, my findings do help shed some light on why mental healthcare can cause suffering among activists and provide some ideas on how policy makers and service providers might progress. In this sense, my work adds to important conversations around what forms of 'care' are worth pursuing and providing (Chase 2019; 266) and what forms of sociality and organisation might be beneficial, especially for individuals experiencing long-term mental distress.

Activists have taught us that mental-health professionals need to better accommodate patients' concerns, even when those concerns challenge the conventions of clinical practice. This includes creating spaces for patients to express themselves freely without feeling pushed into particular categories and treatment pathways. For example, wearing a dirty shirt should not be seen as signifying that a patient has lost capacity or is unable to articulate their needs. Nor should a person's distress be defined as a personal failing for which they are primarily responsible when they also grapple with a low income, unstable accommodation and other challenges. Being more responsive to a patient's circumstances and realities might mean creating room for dialogue in clinical appointments, in which people do not feel compelled into particular trajectories, confessions or narratives, and showing greater appreciation of alternative approaches to

mental distress. Rather than confining provision to a particular service or a particular location, clinicians might consider offering their support in places where patients feel more at ease, especially when patients are experiencing acute distress.[347] Taking patients' needs seriously might mean providing access for self-governed, peer-led groups to buildings free of charge, allowing them to meet unconstrained by time, and without having to comply with donor reporting processes and other administrative requirements. It might also mean assessing the impact on patients of some of the changes that have been introduced into mental healthcare under the guise of democratising provision or improving its efficiency. Here I refer to initiatives such as the digitalisation of therapies and the compression of sectioning procedures.

Understandably, clinicians and other professionals might not want, or be able, to work within unfamiliar, uncertain frameworks that allow scope for the irresolution of distress and healing. Further, few clinicians are prepared to step away from their explanatory frameworks, not least because these are grounded in EBM and procedures that comply with accepted professional standards. Allowing themselves to fully lean into, feel and understand their patients' experiences and perceptions would be a feat of mental gymnastics; a leap into the space 'in between' themselves and their patients—and this is not stable ground. In fact, when one introduces these ideas into clinical settings it is surprising how radical they appear. This became clear to me while I was giving a talk at a professional conference attended by a large number of clinicians. My topic was 'mutuality, listening and healing among activists'. Having outlined the importance of allowing activists ample, unstructured time to draw their own conclusions and 'live out' their distress, I mentioned the lack of agendas in activists meetings. I was met with looks of concern and raised eyebrows among the audience. Bemused, a psychiatrist warned disapprovingly; "That just sounds like… pure chaos and anarchy". This particular professional was deeply concerned about the lack of control and regulation in activists' approaches, which to him, violated important boundaries and fundamentally, people's safety and security.

The Covid-19 pandemic has increased pressure on both the mental-health activist movement and services, which has made it harder for activists to meet in unconstrained ways. As I write this, all three of the networks I worked with, FLL, SAP and RMH, have

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[347] This innovation is already being trialled in some parts of the NHS. See https://www.ucl.ac.uk/pals/research/clinical-educational-and-health-psychology/research-groups/oddessi/oddessi-trial.

ceased gathering as regularly, and many of the buildings they used are closed. But I remain hopeful that we can move toward future(s) in which service providers can work with service-users in mutual collaboration, epistemic humility and an acceptance of the fundamental indeterminacy of mental distress—by resisting comprehensive or universal solutions to mental health problems and developing diverse spaces where persons in distress can be 'let-be' together in order to, perhaps, be able to 'go through' madness and out the other side. I hope this study can be a step toward achieving that.

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