

## Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

### **A Hidden Activism and its Changing Contemporary Forms: Mental Health Service Users / Survivors Mobilising**

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#### **Abstract**

This commentary concerns how the organisation of State welfare benefits in the UK have changed over the last 20 years, arguing that this has had harmful, even fatal, consequences for people with disabilities and particularly those with mental distress of psychosocial disabilities. This current situation may be called that of austerity. The paper describes how a 'hidden activism' has emerged to contest this situation and explains why it is, and to a degree, must be hidden. I then focus on the discourse of responsabilisation where every citizen must take responsibility for embodying the virtues of the good, working person. To ensure this, unemployment has been framed as a psychological problem and psychologists are now employed to 'treat' this problem in order that everybody might enter the world of work. I argue that in current conditions this is not possible for all with mental distress. Engaging then with community psychology, I address the issue of allies and how the absence of attention to mental distress might be remedied by this form of work. I draw on the emerging field of user / survivor-led research in mental health and argue that collaboration with community psychology will not be without problems.

*Keywords:* mental health, austerity, responsabilisation, activism

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In this commentary I will describe a new way in which people who use (or refuse) mental health services are radically disempowered, with an attack on their basic means of survival. This situation is part of the wider policy of 'austerity' introduced progressively in the UK over the last twenty years. The aspect of this I shall discuss concerns welfare benefits although service users are obviously affected by cuts to other parts of the welfare state. The article will describe a concomitant 'hidden activism' whereby the most disenfranchised of citizens try to fight back. This activism is 'hidden' partly for material reasons but also because the concept of mental patients organising for their rights is alien to Western societies so even when this activism enters the public arena it is not visible. I will chart the effects of austerity on that aspect of the welfare benefits system that is targeted at those assessed for their

fitness to work in terms of long-term health conditions and the forms of resistance which this has prompted over the last two decades. I will also consider if there is a place for academics to intervene here by focussing on the question: what kind of social justice movement is this? If mental health service users want equity but not normalisation, what kind of movement are we dealing with here? Finally, the article is focussed on the UK because the kinds of intelligence by which one knows about such activism is not always a matter of public record but of local and personal networks.

The last sentence might be read to mean that I am being 'subjective'. I would like then to introduce the field of user /survivor research, which is where I situate myself intellectually. Although the arguments are complex and varied, this is a field that gives a prominent place to individual and especially collective experience (Bereford, 2003; Faulkner, 2017; D. Rose, 2017; Voronka, 2016). The exact status of experience is a matter of debate but what is agreed is that 'mental patients' have been silenced for centuries, their speech conceptualised as incoherent, meaningless and their defining feature a lack of reason (Foucault, 2013). The embryonic discipline of user / survivor research, in one incarnation named Mad Studies, is an attempt to reclaim that knowledge and that speech and codify it theoretically and in terms of praxis. The key is that the knowledge and experience of the insane is a critical part of any discourse about psychiatry and mental health. It should not be a surprise then that I start by positioning myself in relation to what I will write in this paper.

## Positioning Myself

Because of my own life trajectory and because of the subject of this paper, I must begin by positioning myself in relation to what I will write. I am a service user / survivor academic which should mean I ground my work in activism. It could be argued that working on the 'inside' whilst retaining an 'outsider' identity is itself a form of activism – contesting privileged academic work on what it means to be mad and what are suitable forms of support. That's why I work in a university, the dominant site of knowledge-production although it is certainly not the only way to contest such understandings. However, I would argue that a grounding in activism needs to go further to generate new and challenging forms of knowledge. So it is relevant that in the years 1972-1986 I had another academic career. I entered academia as a social psychologist but found myself drawn incessantly towards critical theory and activism, in the first instance feminism. Between this and my current position lay ten years as a 'community mental patient', not a desirable position. But during that time I became an activist through involvement in the mental health service user / survivor movement and that was a life-changing moment and the start of a journey that is not over. I write this because I am going to discuss austerity, mainly in the UK though the situation is duplicated in many other countries. Part of the enactment of 'austerity' is to cut the public sector and this includes welfare benefits. So I want here to begin by comparing my experience of receiving welfare benefits with those receiving them now. For ten years these were my main sources of financial support. But if I compare myself to people in that situation now, there is no comparison at all. Although it was two years into the Thatcher government in the UK, its welfare policies were hardly formulated and certainly had not begun to bite. Deinstitutionalisation in the UK had not led to the anticipated horrors, murder and violence of course but neither homelessness (Leff & Trieman, 2000). Unlike our American counterparts, we were not living on the streets. One of the early service user groups, Survivors Speak Out, drew up a Charter of Demands which insisted on financial security, but we were not using foodbanks. Today in this environment of austerity, murders by those designated mentally ill continue to be rare events but attempted suicides by people trying to claim what are now the most meagre of benefits

have increased dramatically in ten years, although published statistics make it difficult to be precise. I did not live in fear of the brown envelope as people do now. The 'brown envelope' is the paper in which communications from the Department of Work and Pensions arrive by post and people literally live in fear of their contents. And there are worse things that I shall describe. This situation has led to new forms of mobilisation amongst those with mental distress who are directing energy as much towards policies which threaten the means of survival as towards the psychiatric system as such. And the final thing to say is that this takes its toll. I am reflecting on some of the most marginalised, disenfranchised and so vulnerable members of society and activism requires energy and numbers. People withdraw, people become burned out. There is much mutual support, online as well as face-to-face, but sometimes it is not enough and sometimes people don't make it.

## Academia and “Mental Health”

If I situate myself as a user / survivor academic, this special issue draws upon and interrogates the fields of community psychology or community social psychology and there are methodological similarities between this and user/survivor research. Both take as a main method 'participatory research' although this has multiple methods and meanings (C. Campbell & Jovchelovitch, 2000). Health was a focus early on (Cornwall & Jewkes, 1995) and the same authors a decade later saw promise for participatory research in democratic spaces (Cornwall & Coelho, 2007) although critiques had started earlier (R. Mason & Boutilier, 1996). There has been abundant work on people living with HIV / AIDS (Epstein, 2000; Houston, Osborn, Lyons, Masvawure, & Raja, 2015) as well as some focus on physical disability (Radermacher, Sonn, Keys, & Duckett, 2010). Such work has often engaged large communities or sometimes small organisations. Work on mental health within this body of literature is conspicuously absent. There is Brazilian work with those in distress which claims a participatory tradition (Campos & Campos, 2006; Onocko-Campos, Diaz, Dahl, Leal, & De Serpa, 2017). However, the latter concentrates on the difficulties posed by those with 'severe mental illnesses' in a focus group setting – not just access and ethics but the fact that narratives are fragmented and not coherent. In other words, the illness disrupts the focus group method and the solution is to involve clinicians and managers. This does not meet the criterion of levelling power relations in my view; rather it reproduces them.

Other authors have interrogated the concept of 'community' and I will use this work (Choudry & Kapoor, 2010; Cooke & Kothari, 2001). But one of my conceptual goals is to weave empirical data with concepts of power, individualism and especially the ideas of 'recovery' and 'empowerment' to pose what may be some difficult questions for the wider academic community but also to open some doors, admittedly ones that would be hard to push.

## Current Hidden Activisms

However, before broaching this I will describe some current 'hidden activism' in relation to mental distress and mental health. These have a long history but I will focus on the current mobilisation in response to the austerity policies which had their seeds in the Labour government's introduction of Work Assessments for disabled people in 2002 but which have become progressively stricter since the election of the coalition in 2005 and especially as austerity has been tightened since the success of David Cameron's campaign resulting in the Conservative Party

in the UK coming into power in 2010. Particularly important was the privatisation of the assessment process of fitness to work because this deregulated criteria for who could carry out assessments.

The ostensible reason for the drive to get ‘disabled people back to work’ was that tens of thousands of people had been put on a sickness benefit (‘invalidity benefit’) in order to cut the numbers appearing on the unemployment register. In other words, it was a deliberate ploy by the Labour government to minimise the numbers apparently on the unemployment register and to make it seem as if full employment was in reach as a result of their economic policies. However, this was turning out to be very expensive and together with an ideological shift towards individuals taking responsibility for themselves a policy was progressively forged to enable (or force) people with disabilities, including psychosocial disabilities, into open employment (Beatty & Fothergill, 2015; Scruggs, 2006). The ideological climate was not one where employers and employees might discuss ‘reasonable accommodations’ whereby a person could work safely and effectively in a job. No, the material and cultural environment was hostile with newspapers speaking of ‘scroungers’ not ‘strivers’ and there was a rise in disability hate crime (Brown, 2012).

By 2005, those who would have previously been on ‘incapacity benefit’ were progressively subject to the ‘Work Capability Assessment (WCA)’. This was normally an interview with copious documentation and it is not irrelevant that it was run by a private company whose employees knew little of the effects of ill-health on people’s capacity for work. Those subject to the WCA were divided into 3 groups. There were those found ‘fit for work’ and they joined the existing ranks of the unemployed, at that time termed ‘JobSeekers’. Second were those placed in the Work Related Activity Group (WRAG) upon whom was a duty to attend for various activities to make them ‘work ready’. Finally, was the Employment Support Group (ESA) which, whilst seemingly most like long-term unemployment benefit, required repeated assessments to see if people might be better placed in the WRAG.

## Physical and Mental Disabilities

The WCA is almost exclusively concerned with physical and sensory impairments and limitations:

how far you can walk, what weight can you lift, can you wash, dress and toilet yourself all broken down into the smallest of elements. If you cannot go outside because of fear of open spaces this is not equivalent to being unable to go out because you cannot walk 50 metres and therefore does not attract the ‘points’ which are summed to allocate you to one of the three groups: your terror is at once rendered invisible and penalised.

By 2011 it was recognised that the WCA disproportionately affected people with mental distress as it focused almost exclusively on physical capacities. The Harrington report in 2012 (Harrington, 2012) tried to resolve this with some success in reducing the numbers found fit for work. However, this was very partial. In 2014 Disabled People Against the Cuts (DPAC, 2014) demonstrated using official statistics that people with mental distress, or mental disabilities, continued to be discriminated against at every turn.

In this work, DPAC were joined by a small mental health organisation called the Mental Health Resistance Network (MHRN). This is one of the groups I refer to as comprising a ‘hidden activism’. DPAC itself is to some extent hidden as the idea of disabled people organising for themselves is counter-stereotypical. However, DPAC has some formidable statisticians on board. But the image of the madman or woman as violent or pitiable, unpredictable or hopeless means that groups like MHRN never appear in the mainstream media or popular culture. If they do, they morph into the weak and hopeless, the shiftless, the unemployable or the just plain crazy. That they might have agency and something to say is not on the agenda.

## Old Struggles in New Bottles

But just at the moment rules were relaxed for people in distress, there was a call for increasing 'evidence' to back up a claim for benefits. Letters from GPs were necessary but so too were letters from specialists. In the case of people with mental distress this meant psychiatrists. And this posed a dilemma and a tension. Many of those who had been campaigning on the benefits front had opted out of the psychiatric system but they now needed support from a psychiatrist. Indeed, they needed a diagnosis. Some swallowed hard to accept this or found a friendly psychiatrist but there was another development. A group of psychologists from the British Psychological Society had been developing an alternative to diagnosis known as 'formulation' and they were very vocal going round the country and with a lot of social media activity (British Psychological Society [BPS], 2018). In what looks like a paradoxical move, given the debates about the harms of diagnosis, some of the austerity campaigners contested the psychological concept of formulation saying that they needed a diagnosis to receive benefits. Some went as far as to say psychiatry was no longer the main problem; it was the state and its incessant tentacles. This debate on social media, which I cannot reference, became extremely heated and hostile.

## Austerity and Disabled People in the UK Today

In 2017, NHS digital released the results of the 2014 Adult Psychiatric Morbidity Survey for England (<https://digital.nhs.uk/catalogue/PUB21748>). The figure that caught the headlines was that almost 25% of 16-24 year old women reported self-harm, mainly self-cutting, in the previous year. Suicidal thoughts and attempted suicide had also increased. In, to some, a quite astonishing Foreword, Paul Farmer, Chief Executive of the NGO MIND, pronounced that the reported increases in mental health problems were a result of stigma reduction. That is, 'reporting' had increased to reveal a 'true' and apparently stable state of affairs as people were now less afraid to admit to mental health problems. To some of us, the idea that 25% of young women had been hiding self-harm for decades was laughable although it is clear some do and this is particularly so for those from BAME backgrounds (Pembroke, 2005; Wilson, 2006). But another figure stayed under the radar of press and public reaction:

Benefit status identified people at particularly high risk: two-thirds of Employment and Support Allowance (ESA) recipients had suicidal thoughts (66.4%) and approaching half (43.2%) had made a suicide attempt at some point (Chapter 12, p. 3)

This figure had doubled since 2007. The calculation was consistent with a quantitative study of local authorities which also showed widening inequalities in the rate of suicide attempts with regard to indices of deprivation (Barr et al., 2016) as well as a qualitative study of recipient's responses to the assessment process itself (Garthwaite, 2014). Again, I would argue this figure stayed under the radar, remained hidden, because although we had been encouraged that it was 'time to talk' and celebrities like Prince Harry had indeed talked, the lives, or deaths, of those on the margins of society, the 'seriously mentally ill' were not newsworthy, perhaps even an embarrassment.

This information regarding suicide attempts was not new to those working in the field. Disabled People Against the Cuts (DPAC) had been amassing statistics and cases since 2010 and analysing official data collected well before that. They had in fact brought two cases of violation of the rights of disabled people to Convention for the Rights of Disabled People (CRPD) Monitoring Committee at the United Nations. One of these resulted in a judgement, in 2016, that austerity policies had resulted in 'grave and systematic violations' of the rights of disabled people (CRPD, 2016). This action again involved the small organisation the Mental Health Resistance Network (MHRN). The second was similarly judged and like the first the government declined to act. Then in 2017 the CRPD Monitoring Committee issued its report on the implementation of the CRPD in the UK and again found that

the rights of disabled people, including those with mental distress or ‘psychosocial disabilities’, were violated in the case of nearly every article (CRPD, 2017). They specifically mentioned the treatment of service users from BAME groups in the mental health system especially in respect to coercion: detention and compulsory treatment and now Community Treatment Orders. We have a new Independent Mental Act Review which claims to pay close attention to this issue but neglects to mention that the situation has been in this parlous state for at least two decades (Fernando & Keating, 2008) and has been endlessly brought to the attention of the authorities.

The CRPD explicitly uses the term ‘austerity’ as a reason for its finding that the rights of disabled people are systematically violated in the UK especially in the case of positive rights such as to adequate housing, financial security and community living.

## Psychology Enters the Frame

Three years before the CRPD Committee delivered its judgement, the UK government started to employ what is termed ‘welfare conditionality’ (Nevile, 2008) and at about the same time benefits recipients who received money on grounds of being unfit to work in the long term – Employment Support Allowance or ESA – had their benefits reduced by £30 per week to the same level as those on short-term unemployment benefits. In other words people on long-term sickness benefit (not that it was called that) were expected to live on £73 a week. A discourse of responsabilisation, which had always been present, then began to pervade debates on welfare reform (Deacon, 2005; Patrick, Mead, Gregg, & Seebohm, 2011). In terms of people claiming benefits on grounds of long-term mental distress, this took a particular form. Work was (re)defined as a ‘health outcome’. Employment had always functioned in research and clinical practice as a part of ‘quality of life’ (Stansfeld & Candy, 2006). But now it was firmly positioned as a part of positive mental health (Shanks et al., 2013). And the converse of this was that one could not be mentally healthy if not in the open labour market. This raised protest, physical and discursive, from groups such as the MHRN and the influential FaceBook group Recovery in The Bin (RiTB). The power of social media to initiate new forms of mutual support and ultimately new forms of protest and action should not be underestimated (see, for example, <https://recoveryinthebin.org/2016/03/30/workfare-coercion-in-the-uk/>).

### Welfare Conditionality

Welfare conditionality involved a regime of ‘sanctions’ whereby claimants could have money stopped for several weeks if they missed appointments, including appointments to assess how ‘work ready’ they were. This especially applied to those in the WRAG group. In framing work as a health outcome, not working was framed as a psychological condition and one that might (or might not) be amenable to treatment. This was not a new idea (Perkins & Corr, 2005) but opened the gates to placing psychologists in job centres in 2015 in England. As a result, people could be sanctioned for not attending appointments with psychological professionals. Friedli and Stearn termed this ‘psychocompulsion’ (Friedli & Stearn, 2015). There is a history to these developments in debates about ‘recovery’ to which I shall return. For the moment let us note that it has always been said that, unlike medication, psychological treatment cannot be ‘forced’ on someone. You cannot hold someone down and inject them with CBT. Yet now a way seems to have been found: submit to psychological treatment or be destitute.

There are two other points I would like to make regarding the impact of austerity policies on those with mental distress and how some responded. I have already mentioned one which is the toll this ‘hidden activism’ takes on



those who become involved and especially the leaders. Whilst much takes place on social media there are constant rebuttals to make in terms of written pieces, demonstrations to organise and conferences to attend. The latter can be particularly bitter when seemingly sympathetic conference organisers insist on charging full fees or at least will not cover travel costs. People give up, temporarily or completely, they become unwell. Their arguments are profound, their stories heart-breaking and they are producing critical thought on the streets and the internet. But they cannot go on forever, ironically, unfunded.

The second point to make is that we are talking here of people with long-term mental health conditions. The situations in which they find themselves can nourish their distress. If there is a CCTV camera at the gym is it filming me to give to the Department of Work and Pensions to show I am fit for work? If the man next door sees me going out regularly will he inform on me to the DWP? Is the State deliberately trying to kill us? Many have said we are reaching the edges of Nazism in some quarters but for people like this they can come to believe their life is in peril. We did after all go to the gas chambers first. I do not believe these things but I can see how they could be believed. And my experience of the welfare benefits system was benign as I have said.

## A Social Contract?

But what does this mean for the 'social contract' between citizen and state; of Nye Bevan's aphorism *From Cradle to Grave*? There was always a social category of the 'undeserving poor' but now this seems to have been expanded exponentially to include people who hitherto were explicitly excluded from the open labour market at least since the Enlightenment and the industrial revolution in the Industrialised West (Foucault, 2013; Foucault, Stastny, & Sengel, 1995). And once unemployment is positioned as a psychic failing then those already diagnosed are the first suitable cases for treatment: IAPT for those with 'common mental disorder' and psychologists by coercion in the case of people with a diagnosis of 'serious mental illness'. Increasing Access to Psychological Therapies (IAPT) is a scheme targeted at those with 'common mental disorders', such as anxiety and depression which though ostensibly therapeutic is a major tool to cut the numbers on sickness benefits. What has been termed 'psychocompulsion' is focused on daily living skills and normalisation in order to place people in jobs. As such, we have a new social contract where citizens have responsibilities to 'achieve' and 'contribute' (which means economically through paid work) which is defended by many (Fleurbaey, 2008) and the Work Capability Assessment is barely criticized in mainstream evaluations (Litchfield, 2013). It is true that the original Assessment was recognised as 'sometimes inappropriate' to people with mental health problems and was adjusted as a result (Harrington, 2012; Litchfield, 2013). Nevertheless, reading the advice given by the NGO Rethink to persons filling out this form makes me imagine nothing less than a labour of humiliation (<https://www.mentalhealthandmoneyadvice.org/en/advice-topics/welfare-benefits/will-i-need-a-work-capability-assessment-to-claim-benefits/how-do-i-fill-in-the-health-questionnaire/>). Bevan's dream appears to have evaporated as all claimants, but particularly those with disabilities and therein those with psychosocial disabilities, are positioned as everything from scroungers to psychological failures but, interestingly not only as 'mentally ill'. Everyone must strive to be normal and the normal / abnormal boundary is shifting in both content and where one draws the line (McWade, 2016). But however these subtleties work they pose mental health issues as the most intractable problem for the state. In turn, austerity policies would appear to have given rise to an increase in those in distress and diagnosed (N. Rose, 2018) and Paul Framer is wrong in his assumption that we live now in a tolerant society where everyone feels able to be open about mental illness. Depression and anxiety maybe but hearing voices, mania or believing that the state is out to get you are certainly not part of public discourse, benign or otherwise.

## Resistance

I have mentioned grassroots organisations such as DPAC and the MHRN and there are others such as Black Triangle. Kindred MINDS, a BME network, has just published a Manifesto for Black people in relation to the mental health system which has caught the eye of the UNCRPD. Some of this work is very local (two of the organisations cited are active mainly in one Borough of London which happens to be where I work!). But local organisation, be it protest, campaigning or support seems to be typical and national connections are made through social media especially on closed Facebook groups. Local organisation was also found to be predominant in 2003 (Wallcraft, Read, & Sweeney, 2003). However, there is a national organisation of users and survivors of mental health services: the National User Survivor Organisation (NSUN) ([www.nsun.org](http://www.nsun.org)). This is a network of networks and includes the Survivor Research Network (SRN). They struggle to survive. In 2017 it was estimated that 25% of their membership groups had closed and this seemed to be associated with the outsourcing of state provision in health and social care such that big charities like MIND and RETHINK were in receipt of £b to provide services previously provided in statutory organisations. And yet, it is often small and local organisations where service users get the support they need. There is little research here – this is my informed impression.

There is one thing that connects these embryonic organisations of resistance on the part of mental health service users and survivors and that is a deep distrust of anything mainstream. This includes mainstream academics. As an example, we repeated a ‘consultation’ exercise on grassroots priorities for research (Robotham et al., 2016) with people from BME communities who had not known about or felt alienated from mainly white groups. Whilst some of the research priorities they suggested were similar to the mainstream groups, particularly medication although differently inflected, they also suggested we stop ‘treating us like guinea pigs’ and ‘research yourselves and the white, racist institutions you inhabit’. NSUN too tried to collaborate with the umbrella organisation the Mental Health Alliance on new Mental Health legislation but when they saw the questionnaire and consequent results they felt compelled to withdraw and wrote a long statement on what Mental Health Law based on rights could look like and their conditions of involvement with non-survivor organisations (<https://www.nsun.org.uk/news/nsun-members-to-get-involved-in-the-mental-health-act-review>). The Vice-Chair of NSUN is committed to a form of ‘coproduction’ but it has to be on the terms of the group that is marginalised (Needham & Carr, 2009). It is interesting that the person who founded the mental patients liberation movement in the USA, Judi Chamberlin, and who held out for user-controlled services for 30 years, in one of her last articles talked about collaboration with service providers. But her condition was that all parties had to be aware of their power position and lay that on the table from the start (Chamberlin, 1978, 1990, 2005). To be frank, I do not know if that is possible in mental health. But we can dream.

### What Kind of Social Justice Movement Is This?

And there is more of a conceptual issue here. In the original framing the terms of this special issue, the editors say “We suddenly find ourselves in an era when these liberal values are no longer taken for granted, and where the social preconditions for relations of dialogue, trust and mutual respect have been eroded.” I would argue that these ‘relations of dialogue, trust and mutual respect’ were always deeply controversial in social movements in mental health and that this has been so for 30 years, spanning more than the lifetime of community and critical psychology (P. Campbell, 1985/2005, 1996, 2001; P. Campbell & Rose, 2011; The Survivors History Group, 2012). The role of ‘allies’ both clinical and academic has always been contentious and fraught with problems. I remember this as my own local user group became progressively user-led as there was something about mental



health service use that, hard as they tried, allies just did not 'get' and so they hindered the development of a collective discourse that could change understandings of mental distress and new forms of support. This was a very common situation (Faulkner & Thomas, 2002; Rogers & Pilgrim, 1991) although, as Judi Chamberlin's trajectory shows, we kept trying. Added to this, the 'community' at stake here is not homogenous and there have been particular struggles for BME communities who felt it impossible to join with the mainstream user movement because it refused to understand that racism was fundamental to the experience of Black service users (Francis, David, Johnson, & Sashidharan, 1989; Kalathil, 2008, 2010; King, 2016). Similar arguments have been made from an LGBTIQ perspective (Carr, 2014) and intersectionality is high on the agenda.

This can all be framed as an integrative / separatist debate and there would be some legitimacy to that. But in my view what is happening here is a call for attention to local specificities, a rejection of universalist epistemology and methodology as well as a politics that rejects both the predominance of mainstream psychiatry and, even worse, the transplantation of its activities to very different local situations be they diasporic or in the Global South (Davar, 2014). Insofar as that attention is appreciated and also extends to 'alternative' ways of offering support, then engagement is possible but will always be precarious (Bayetti, Jadhav, & Jain, 2016).

So what kind of social justice movement is this and how can community and critical psychology support it? The first thing to say is that there will always be suspicion – we are talking allies and academics both of whom, at best, misconstrue. There is a rejection of liberal values here but it is not of the order of supporters of Brexit or Trump. The rejection at its simplest, I would argue, is because 'liberal' and 'neoliberal' values privilege the individual and what we are told is that we are *individually* pathological, that there is something wrong with our brain or our person, our cognitions or our emotions, at worst, in the diagnosis of 'personality disorder', of our whole self (Bonnington & Rose, 2014; Jones & Brown, 2012; D. Rose, 2014b). So this social justice movement, if such it be, is not one that denies distress, not at all, but explains that distress socially and fights individualism by collective endeavour. Of course this comes in stronger and weaker forms (D. Rose, 2017; Jones & Kelly, 2015). This collectivity is not homogenous at all and for some to speak of the 'mental health user movement' as a 'community' is patently absurd because it consists of 'small groups of unrepresentative people' who are either sicker (angrier) or more articulate than 'ordinary' patients (but never both at the same time). These arguments were addressed 15 years ago and nothing has changed there (D. Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2002). To summarise, there is a difference between being 'representative' and striving to 'represent' a collective discourse of contention, collaboration and change. Psychology positions us as 'unique individuals' to be treated with 'personalised medicine' and as such rips us of context and constraint (Israel et al., 2014). To the extent that community psychology and other academic disciplines approach the 'community' and not a 'collection of individuals', for me at least it is on the right tracks.

But in the UK and elsewhere in the Industrialised West, mental health services are trying hard to prevent us from even associating with one another as day centres are closed in the name of preventing 'dependency', small groups lose their funding and this is disproportionately so for BME groups, secondary services are discharging people to GPs in their thousands and, ironically, there is now a burgeoning of research into 'isolation' most of it not yet published but with precedent (Perese & Wolf, 2005). The figure that '1 in 4' people suffer from mental illness again assumes some random set of individuals across a homogenous community. But this '1 in 4' is socially structured, structured by inequalities as we have known for more than half a century (Hollingshead & Redlich, 1958) and 'mental illness' is not a faulty brain or faulty person but a primarily socially determined response to adversity that requires social solutions (N. Rose, 2018). By closing and disallowing collective spaces and supports it seems

liberalism still rules here as individuals are responsible for their own wellbeing. Social networks and social capital are alluded to but very poorly conceptualised by the field (Perry & Pescosolido, 2015; Webber et al., 2014).

## The Dominance of 'Recovery'

To try to illustrate the remarks above I shall conclude by alluding to a specific debate. It exemplifies the point concerning individualism and revolves around the concept of 'recovery' and its potential for 'normalisation'. I shall do this briefly as I have written about it, including its personal impact on me, elsewhere (D. Rose, 2014a).

### The Road to Recovery

Recovery discourse has taken hold as an 'alternative' to mainstream psychiatry and its focus on medication (Repper & Perkins, 2003; Slade, 2009; Slade et al., 2014). Recovery is about 'personal', that is 'individual' recovery and although the importance of 'social networks' is noted, it is the individual who must set goals (their own goals) and achieve them. There was a literature on recovery in the 1990s and later and its focus was on the importance of peer support (Deegan, 1988; Mead, 2014; O'Hagan, 2004). But the professional literature focuses on 'guiding' the person to a position of 'hope' (we always emphasised that) where they can take their place in society and in particular where they can work. This has been conceptualised as a form of 'normalisation', as forcing people to be as like the image of the 'normal' citizen as possible (Harper & Speed, 2012; McWade, 2016; D. Rose, 2014a) and linked to austerity and neoliberalism. And of course it is not only those in mental distress who are enjoined to be normal, contributing, self-actualising members of society. Political contexts position and shape subjectivity profoundly for all (Ransom, 1997; N. Rose, 2009). But those in distress cut an emblematic figure.

So in mainstream circles one measure that is used to assess an individual's recovery is the 'Recovery Star' (Dickens, Weleminsky, Onifade, & Sugarman, 2012) whose points represent goals and whose spokes say how far they have been achieved. In response, the Face Book group Recovery in The Bin has responded with the 'Unrecovery Star' (<https://recoveryinthebin.org/unrecovery-star-2/>). The points on the Unrecovery Star are not goals to be achieved but reasons – such as racism, poverty, patriarchy and transphobia – why recovery is not possible for many users and survivors under current conditions of existence. It should be made clear that for many it is not a question of a desire not to work but that most available work today for people with mental distress and fragmented cvs is either unattainable or has been shown in a systematic review to make the kinds of work on offer detrimental to mental health (Kim & von dem Knesebeck, 2015). At the same time, it is my view that some people are so intensely affected by their mental distress that supports are constantly necessary and work not possible at all. Additionally, nobody has really addressed the question of what 'reasonable adjustments' might mean for those severely affected by distress. They are not the equivalent of ramps and toilets accessible for disabled people and the ones we can think of are probably unacceptable to nearly all employers. For example, to say from the outset I will probably have at least 3 months per year when I am unable to work will kill any possibility of employment. But, for some, this is the reality. On the other hand, there are those who go for inversion, embrace their madness and promote MadPride. This is an international movement now but there was an early book in England (Curtis, Dellar, Leslie, & Watson, 2000). Recovery need not mean 'being normal' but accepting your madness and making the most of it when you can often because you have the first-hand experience allowing support to others when in similar distress. This is the basis of real peer support (Faulkner & Kalathil, 2012). This is not to say that 'normality' is not a goal of many – the situation is complex and so is the 'community' (Lofthus, Weimand, Ruud, Rose, & Heiervang, 2018).

## What Kind of Activism Is This?

So in terms of this special issue, we find a kind of activism that is neither pre- nor post-liberal, that is suspicious of the mainstream and experts, yes, but promotes a kind of radical left politics that does not sit easily with the ideas of some radical thinkers but not for the usual reasons. This activism is barely visible socially because 'the mad organising' is an oxymoron and there are material conditions for not being persistently open. It is hidden, it is suspicious and it is angry but with a righteous anger. The title of a film shown on Channel 4 in the 1990s was '*We're not mad we're angry*'. There is then distrust of those who would 'empower' us because to accord power is structural not psychological as has been argued for some time (Swift & Levin, 1987). It has been well-argued that handing back power to a community, or co-producing change, is not easy whether attempted by large organisations (Henkel, Stirrat, Cooke, & Kothari, 2001), or NGOs apparently on the side of marginalised groups (Choudry & Kapoor, 2010) or research (Campos & Campos, 2006). On the whole, I would argue that the wider academic community including community psychology has not thought about madness, about distressed people as activists or as survivor researchers. We represent a liminal group but perhaps arguments about power, individualism and normality as well as a very different kinds of suspicion of experts can be helpful. Many experts have talked about us from positions of authority: now we are speaking back. Maybe an expertise that has been silent can learn and be helpful.

## Conclusion

I have described a hidden activism and the political and discursive arguments which ground and frame it. I have, it will be noted, made use of official statistics. But facts, as we know, do not speak for themselves and these figures are positioned within a particular discourse of exclusion, marginalisation and rights. 'Facts' may be used to produce alternative truths as long as they are grounded in peoples conditions of existence which may be wretched (Harding, 2008). I have the impression, I may be wrong, that insofar as the wider academic community (outside the 'psy' disciplines) thinks about madness and distress it is from an ethical position of wanting to help, to ameliorate suffering and to do this not from a position of containment and control but, to use a term, in order to 'empower'. It may even be that what I have written here has intensified that sense: something must be done! But if other academic disciplines are to do anything effective they must get rid of every last vestige of charitable but patronising approaches and be ready to face anger, suspicion and dark, sometimes shocking, humour.

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