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Maladjusted to injustice? Political agency, medicalization, and the user/survivor movement

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ABSTRACT
This paper examines the factors that shape the political agency of psychiatric service users/survivors. I begin by outlining an Arendtian framework for thinking about political agency and its sources. I then use this framework to explore the politically empowering and disempowering factors that users/survivors face, drawing upon evidence from the writings of user/survivor activists and organisations, newspaper articles, and psychiatric professional publications, published in the UK between 2006 and 2016. The insights of this examination are of wider interest for two reasons. Firstly, they elucidate the obstacles to political action facing the growing number of people diagnosed with mental disorders. Secondly, they suggest what a future in which politics is increasingly fought out in medical terms means for citizens' political agency generally.

1. Introduction

Mental suffering abounds in the modern world. Diagnoses of and prescriptions for mental disorder have been surging for decades (Steel et al. 2014). This surge appears to be at least partly a result of various kinds of mental suffering increasingly being understood and treated as symptoms of mental disorder (e.g. Horwitz and Wakefield 2007, 2012); that is, they are being medicalized. And while some forms of joy are medicalized as well (such as elation, in case of mania), a perusal of the latest edition Diagnostic and Statistical Manual of Mental Disorders (APA 2013) can leave one with little doubt that suffering is a much more likely subject of psychiatric diagnoses.

Scholars have long warned that framing suffering in psychiatric terms may depoliticize problems by individualizing and disconnecting suffering from the contexts in which it has arisen and is maintained (e.g. Cohen 2016; Conrad 1992; Horwitz and Wakefield 2007; Moncrieff 2010; Rimke 2016). In saying that medicalization is or can be depoliticizing, these scholars usually seem to imply that designating suffering as a medical problem diminishes the ability of an individual or group to describe and act on it politically. The increasing prevalence of mental disorder, and correlatedly psychiatric concepts, means that these concerns have perhaps never been more urgent for those of us who are interested in political agency and citizenship. However, they are not new. The so-called antipsychiatrists of the 1960s and 1970s also warned of the depoliticizing effects of
labelling suffering as mental disorder. Responding to these earlier interventions, Sedgwick (1982) argued that the antipsychiatrists were mistaken about the political valence of psychiatric diagnosis. In their efforts to deconstruct and challenge the idea of mental illness, antipsychiatrists failed to see and indeed obscured the potential for psychiatric concepts to work as focal points for a new kind of political contest, what Sedgwick called ‘psycho politics’ (see also Cresswell and Spandler 2016). ‘Mental illness’, Sedgwick insisted, can be a ‘critical concept’ in the hands of those who are ready to ‘make demands’ upon the health service facilities of the society in which we live. Differently put and contrary to contemporary critics of medicalization and psychiatry, he appeared to suggest that framing an experience in medical terms can enhance political agency.

If we want to understand how the medicalization of suffering impacts political agency, where better to look than the individuals and groups who are already acting, or trying to act, politically under the stigma of mental disorder? Some people diagnosed with mental disorders have rejected the current state of mental healthcare and are acting with others to challenge the authority of psychiatry and the public perception of mental disorder. These individuals and the groups they have formed are sometimes collectively referred to as the psychiatric user/survivor movement, indicating that it consists of mental health service users and self-described survivors of psychiatric services and social exclusion. This movement’s members are subjected to empowering and disempowering factors that can inform our understanding of the political impact of medicalization. Not only have many been formally medicalized through a diagnosis; they also self-consciously struggle to politicize experiences and issues that sit within the supposedly apolitical relationships and spaces of psychiatry and medicine. While most have not been deprived of the formal rights of citizenship, we shall see that user/survivor activists face other forms of marginalization or exclusion and that various aspects of public and psychiatric discourse maintain and exacerbate these conditions. Given Sedgwick’s death in 1983, he was unable to comment how this movement, its challenges, and the possibilities for psycho politics have developed since then; topics which this paper picks up. The case of the user/survivor movement is also of wider interest for at least two reasons. Firstly, it elucidates the obstacles to political action facing the growing number of people diagnosed with mental disorders. Secondly, it suggests what a future in which politics is increasingly fought out in medical terms portends for the political agency of citizens in general.

Drawing on the writings of user/survivor activists and organisations, newspaper articles, and psychiatric professional publications, published in the UK between 2006 and 2016, this paper examines the factors that shape the political agency of users/survivors. The historical timeframe and source selection mean that some more recent activities and certain dis/empowering factors do not come into view in this examination. Social media, for example, plays an important and often empowering role in the lives of users/survivors – though it is not without its own dangers. However, by focusing on other sources, such as on what traditional print media say or do not say about the user/survivor movement, this paper elucidates factors that shape the political agency of users/survivors with respect to other, but no less important, publics, such as medical professionals, policy makers, and other groups of citizens who may determine the success of the movement’s causes.

I begin by sketching out an Arendtian framework for thinking about political agency and its sources. After introducing some major user/survivor groups and organisations, I proceed to consider representations of user/survivor groups in the news media and the
appropriation of user/survivor concepts in mainstream mental healthcare affect the political agency of activists and others with mental disorders. In conclusion, I provide a summary and reflect briefly on what the user/survivor case reveals about political agency in an era of increasing medicalization.

2. Arendt, political agency, and dis/empowering factors

I understand political agency as the individual’s capacity to act in concert with other people to shape or respond to public issues. I have borrowed the term 'public issue' from C. W. Mills, who uses it to refer to a problem that an individual shares with others and sees as requiring structural change on a group, community, or societal level. But the definition is largely derived from the political thought of Hannah Arendt, according to whom action in concert generates power.\(^4\) Arendt’s work calls attention to several factors that may enhance or diminish political agency in this sense, notably: affiliations, i.e. non-dominating relationships to other people willing to act together for a shared purpose (e.g. Arendt 1972, 95–96); spaces, in which individuals can gather to act (e.g. 2005a, 170); things and tools, which enable individuals to be seen and heard as well as to see and hear others (e.g. 1998, 52); laws and institutions, which generate and protect opportunities for individuals to act (e.g. 2005b, 336); and concepts, which permit individuals to perceive and communicate their problems as amenable to political action (e.g. 2007, 284, 1972, 130).

In relation to the user/survivor movement, concepts play a particularly prominent role. Psychiatric concepts are both targets and tools of the political contests in which user/survivor activists are involved. Part of what these activists are contesting is that their experiences have been medicalized. In other words, their experiences have been brought within the ‘conceptual scope’ of medicine through a diagnosis (Davis 2010), making them subject to unwelcome interventions, pressures, and prejudices. At the same time, the psychiatric concepts that have been used to describe them also enable and sustain affiliations between activists within the movement, and, as Sedgwick’s comment above suggests, psychiatric concepts may also increase the power of activists’ demands, at least, as I will argue later on, in certain instances.

Given the centrality of concepts, it might seem an odd choice to draw on Arendt for a theoretical framework. She is, after all, probably best known for her thinking on the relationship between political action and affiliations, space, and law. But the importance of concepts to Arendt’s idea of political action can be seen both in the style and substance of her political thinking. Much of her political thought is devoted to recovering and explicating concepts – e.g. ‘freedom’ and ‘authority’ (Arendt 1961) – and distinctions – e.g. between ‘the private realm’ and ‘the public realm’ (1998) – that enable individuals to recognise and use power to shape the world in concert with others. Practically, for her, this involved subverting concepts that depoliticize people’s relationships to one another and the world they share. To act politically, individuals must first recognize that some problem is not natural or necessary, but a shared issue resulting from and/or amenable to human action or inaction. They must, as Arendt (2007, 284) aptly put it, ‘cut loose from the world of fancy and illusion, renounce the comfortable protection of nature, and come to grips with the world of men and women’. Some concepts – which I will call empowering concepts – enable us to ‘cut loose’; they help us to perceive a problem as political, provide us with the shared terms we need to act in concert, and enable us to convince
others that our concerns matter. Other – disempowering – concepts maintain the ‘illusion’ that the world and the people in it are the way they are, and that ordinary individuals can and should do nothing about it; they obscure the political meanings of experiences and the possibilities for action, and undermine our credibility in the eyes of others or even ourselves.

As mentioned, many critics of medicalization and psychiatry suggest psychiatric concepts are disempowering. To see why, it is helpful to understand dis/empowering concepts as forming part of people’s hermeneutical resources, that is, the resources they use to make sense of the world (Fricker 2007; see also Wardrope 2015). Contemporary culture and discourses seem rife with disempowering concepts – although, as the growing literature on epistemic injustice highlights, the hermeneutical resources of some groups contain more than others (see Medina 2012). Psychiatric diagnoses and related concepts appear to be prime examples of this. They describe problems on the level of the individual, frequently in biological terms, and prescribe courses of action that the individual must follow if she wants to be cured or, at any rate, avoid greater suffering. Compared to many moral and political concepts, which are publicly and essentially contested, psychiatric concepts are relatively rigid and authoritative. They stem from institutional spaces that privilege the words and deeds of scientists (Arendt 1998, 271). In virtue of their scientific authority, psychiatric concepts, where used, tend to skew the hermeneutical resources toward psychiatric understandings of problems, marginalizing other explanations – such as individual abuse or social discrimination – in medical and political contexts (Crichton, Carel, and Kidd 2016; Kurs and Grinshpoon 2017). As Mary Boyle (2011) argues, in a suitably Arendtian tenor, psychiatric diagnoses can make ‘the world go away’.

For these reasons, much of the discussion below will focus on the concepts associated with user/survivor activism. But other factors – such as affiliations and spaces – will also come into view. This is because the dis/empowering effects of concepts cannot be fully disentangled from the other five factors. They are interrelated, such that an advantage or deficit in one factor may correlate with advantages or deficits in others. If individuals lack spaces within which they can meet and talk, then their affiliations are likely to deteriorate, and they become less likely to develop concepts that enable them to identify and act on public issues. Similarly, if individuals lack the concepts to understand particular issues as shared and open to change, they are less likely to gather to talk about them, and so on.

Moreover, whether a concept is empowering or disempowering depends on its relationships to other factors, and on the context in which they are deployed. These are all tendencies discernible in the context of the user/survivor movement, as we shall now see.

3. Welcome to the movement

There is a diverse range of groups in the UK and other parts of the world that contest various aspects of psychiatry. Some – such as the Canada-based Coalition Against Psychiatric Assault (2019) and its internationally-prominent intellectual leader Bonnie Burstow (2015) – advocate for the abolishment of psychiatry. Others – such as the Hearing Voices Network (2019a) – challenge the standard uses of psychiatric diagnoses and treatments. Still others – such as the National Survivor User Network (2019) – focus on advocating for increased service-user involvement in psychiatry and mental health
policy, meaning that they want those with first-hand experiences of mental distress to shape its concepts and practices. This simplified outline overlooks many views represented within the movement, but it gives us a sense of the lay of the land. The term ‘user/survivor movement’ might itself be slightly misleading since some groups that fall within its scope may have few values or goals in common. However, what they share are political ambitions to reshape relationships, spaces, laws, technologies, and concepts that are ostensibly apolitical, shrouded in scientific authority. Activists within the movement (e.g. Gorman et al. 2013; MindFreedom International 2011, 20; see also Coleman 2008) have often invoked Martin Luther King’s praise of maladjustment in the face of injustice:

Psychologists have a word which is probably used more frequently than any other word in modern psychology. It is the word ‘maladjusted’… Well, there are some things in our social system to which I am proud to be maladjusted and to which I suggest that we ought to be maladjusted. I never intend to adjust myself to the viciousness of lynch-mobs… the evils of segregation and discrimination [or] the tragic inequalities of an economic system which takes necessities from the masses to give luxuries to the classes… History still has a choice place for those who have the moral courage to be maladjusted. (King 1997)

In the spirit of these words, user/survivor activists have rejected the idea that the causes of their subjective suffering reside solely within their bodies or minds and can be dealt with through medical means alone; they have determined that the causes of their suffering are at least partly political and must be dealt with as such, in effect, regarding themselves as maladjusted to injustice.

User/survivor groups constitute empowering factors in their own right, by providing medicalized and suffering individuals with affiliations, that is, others with whom to explore and act on shared issues. But they also give individuals access to other empowering factors – spaces, tools, and concepts – linking the individual into a ‘web of relationships’ that, potentially, reaches far beyond any given gathering and amplifies the effects of their actions. We can discern these factors and the political agency they can give rise to in the relatively short-lived, but prominent, British user/survivor group Mad Pride. Started in the UK in 1999, its founders saw the struggle of users/survivors as a continuation of the civil rights struggles of the twentieth century (Abraham 2016). The ethos of Mad Pride was summed up by one of its co-founders Barnett (2008) as follows: ‘If you’ve got a problem with mad people it’s your problem’. As the Black and Gay Pride movements, Mad Pride activists see the re-appropriation of words used to shame and discriminate as both a means and an end. Activists pursued this through a variety of provocative names, slogans, and practices. For example, between 2006 and 2008, they held an annual arts and mental health festival in London named ‘Bonkersfest’. It was also common for activists to refer to themselves and their peers as ‘mad’, ‘bonkers’, or ‘nutter’. As we shall see, some commentators were offended by this tactic. Mad Pride activists themselves were well-aware of this: ‘Many people will find our casual use of words like “mad” and “nutter” strange’, an anonymous activist wrote in a local UK newspaper. ‘However, we feel that reclaiming the language of madness is empowering. It is hard for someone to belittle you as “mental” when you are already saying, “Yeah, I’m mad. Officially”’ (The Bath Chronicle 2010). Notwithstanding, or perhaps because of, their controversiality, such repossessed terms formed a central part of the empowering factors of Mad Pride and remain important to the user/survivor movement. They are a hermeneutical resource
that activists can use to relate their subjective suffering to established issues and to elucidate shared experiences of discrimination. These concepts also constitute and reconstitute affiliations between individuals and organisations like Mad Pride and scholarly networks like Mad Studies.

After several, fairly well-publicized events and protests in the first decade of the twenty-first century, Mad Pride fizzled in the UK. By 2012, it was largely inactive. One reason for this was apparently the founders’ inability to maintain the organisation over the longer term (Abraham 2016). And while it may not endorsed by those founders, I would suggest that another possible reason is that the push to include users/survivors in the research and development of psychiatric practice – advocated by Mad Pride among others – has been quite successful in the UK, at least insofar as it has become part of mental healthcare policy and practice (e.g. Department of Health 2012; cf. McDaid 2010). Another arguable success is the popularization of what is called ‘recovery’ or ‘the recovery model’. Often contrasted against the medical model of diagnosis and treatment, which critics say myopically focuses on symptoms and biological functioning, the recovery model favours a holistic approach, de-emphasizing the use of medications, aiming to help suffering individuals to (re)gain a ‘personal process, way of life or attitude, involving the growth of new meaning and purpose beyond the effects of mental illness’ (Deegan 2003). The recovery model has been widely endorsed, including by the UK Government (Department of Health 2011). This ‘mainstreaming of recovery’ (Rose 2014) is not unproblematic however; later in the paper, I consider further how the recovery model and user involvement in healthcare affect the political agency of user/survivor activists.

No matter the reason, the timing of Mad Pride’s flagging in the UK is notable, given the debates raging at the time over the forthcoming fifth edition of the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The DSM lists and provides diagnostic criteria for recognized mental disorders, which are used in mental health care in the US and in research across the world. Along with the World Health Organization’s International Classification of Diseases (ICD), it is the dominant classification of mental disorders internationally (Cooper 2014). In the US, the DSM revision process had become a catalyst for protest, involving several user/survivor groups (Bossewitch 2016). Nevertheless, the actions of Mad Pride continue to shape the world, as illustrated, for example, by activists from Germany to India raising the Mad Pride banner. So, beyond whatever concrete influence it may have had on policy, Mad Pride contributed towards establishing and developing empowering concepts that frame the suffering of people with mental disorders as political rather than helping them and others to undermine the ‘illusion’ that this suffering is purely a medical concern.

4. Users/survivors in the news media

Mad studies scholars have highlighted the importance of social media, podcasts, and other alternative media for the user/survivor movement. Woods, Hart, and Spandler (2019), for example, stress the role of such spaces in ‘illuminating aspects of experiences which are painful and difficult to articulate’. Since many of these spaces are deliberately hidden and exclusionary, they do not seem to conform to Arendt’s (1998, 51) own idea of public space as a place that admits all citizens and subjects everything within it to ‘the implacable, bright light’ of collective scrutiny. But the dimmer, shared spaces of social
media or a basement meeting room can evidently be empowering too. Reflecting on the limits of Arendt’s notion of public space, Butler (2015, 55) rightly notes: ‘Sometimes political action is more effective when launched from the shadows or the margins’. Among Arendt’s own examples of this was the ‘public’ space instituted by the members of the French resistance during the Nazi occupation, a realm which ‘was hidden from the eyes of friend and foe’ (Arendt 1961, 3). Such semi-public spaces, to which admission is restricted to certain individuals, can play and have played a critical role as political incubators from which dissenters can launch into wider public discourses (Mansbridge 1996, 56–59). The danger, however, is that such spaces become ‘self-enclosed ends-in-themselves’ (McNay 2014, 122), i.e. spaces where suffering people go not to find a way to change the world, but to escape it in the company of other sufferers. The insular intimacy and homogeneity that may be found in such spaces, Arendt (1995, 12–14) warns, is a strong but dangerous temptation for the pariah, as for anyone at odds with the world. In this shape, spaces – and the affiliations formed within them – can become politically disempowering rather than empowering; this may be a real danger of some online user/survivor spaces.

With these considerations in mind, much can be gained from focusing on traditional news media, which more closely conforms to Arendt’s idea of public space as an arena of harsh visibility. While news media are of course exclusionary as well – albeit in ways that are quite different from those of, for example, closed Facebook groups – their representations of the user/survivor movement and associated ideas both shape and are shaped by the attitudes of larger and more privileged publics than those found on user/survivor social media. Therefore, it is notable that over the past decade user/survivor groups have received scarce attention in British newspapers. Searching in the ProQuest database for news articles containing the terms ‘Mad Pride’, ‘Hearing Voices Network’, ‘survivor movement’, ‘user movement’, or ‘recovery model’ published in Britain between 2006 and 2016, I found 31 articles. Many referred to user/survivor organisations only in passing, frequently describing them as anti-stigma groups or providing no elaboration. When it comes to what little in-depth coverage the movement has attracted in the national British media, judgments have been mixed.

References to the Hearing Voices Network (HVN) were generally positive. HVN is a support and advocacy group for people ‘who hear voices, see visions or have other unusual experiences’; it challenges the idea that these are necessarily symptoms of mental disorder that require cure or treatment. Articles mentioning the organisation often represented it as an important resource for individuals who experience voice-hearing. Some uncritically relayed one of the organisation’s most controversial principles, namely, that voice-hearing need not be a symptom of mental disorder. Newspapers usually portrayed HVN as a support group without mentioning its political advocacy for reforming mental healthcare. This partly explains why HVN has largely avoided the criticism that groups like Mad Pride has faced in certain quarters of the British media. However, the conspicuous lack of political context in these articles also shows how news media, as public spaces, can disempower activists within HVN and the user/survivor movement generally. There are deep tensions between HVN’s approach to mental disorder and mainstream psychiatric practice. Among the most salient of these are perhaps the former’s depathologization of voice-hearing and its rejection of psychiatric diagnosis (HVN 2019a, 2019b; cf. Pierre 2017; see also Pilgrim 2005). The failure to
mention these tensions and the political contestation surrounding them gives the impression that HVN is simply another component in the cohesive British mental healthcare system.

Some media commentators have been explicitly critical of user/survivor groups. Among these is The Guardian columnist Allan (2006, 2007), who has written regularly about mental health issues for over a decade and discussed Mad Pride at times, from the perspective of someone who has herself struggled with mental disorder. Since Allan and Mad Pride activists appear to share views on multiple issues, Allan’s repeated use of her national pulpit to criticize Mad Pride is surprising. Her gripe with the group appears to stem primarily from its claim that what psychiatrists call mental disorder can be a central aspect of people’s identities. In one column, Allan argued that these efforts romanticize mental disorder. ‘[M]ental illness is not an identity’, she declared. ‘Mental illness is an illness, just as cancer is an illness; and people die from both’ (Allan 2006; see also Rashed 2019, 28–29). Invoking a common metaphor between mental disorder and cancer – long promulgated by the pharmaceutical industry and condemned by user/survivor activists and critics of psychiatry – Allan implies that Mad Pride activists fail to understand the true nature of suffering that they and others with mental disorders experience.

Criticism of this kind – which suggests that user/survivor activists and other critics of psychiatry misguidedely and dangerously romanticise, trivialize, and/or stigmatize mental disorder because of a failure to understand what mental disorder really is – seems to be fairly rare in Britain. Allan’s criticism does resonate, however, with views expressed in US news media (e.g. Friedman 2012; Wall Street Journal 2014) as well as by some leading US psychiatrists (e.g. Krystal 2012; Lieberman 2013). By contrast, British psychiatrists do not generally appear to engage in these kinds of attacks on critics of psychiatry, user/survivor activists included. The relative absence of open hostility is probably related to – though not wholly explained by – user involvement in mental healthcare and research in the National Health Service (NHS), which has been institutionalised over more than two decades (see Rose 2015). Consequently, British psychiatrists are more likely than their US counterparts to encounter and have to take into account user/survivors’ criticism of their profession and its methods. The institutionalisation of user involvement, recovery, and other concepts that have emerged from the user/survivor movement seemingly pose different threats to the political agency of activists with mental disorders however, which we shall look at next.

5. Depoliticizing recovery

User/survivor activists may not suffer overt attacks from British psychiatrists. But they do face subtler disempowering factors. I suggested earlier that re-appropriated concepts such as ‘mad’ and ‘bonkers’ serve as empowering factors for user/survivor activists, helping them to articulate their suffering as public issues. Other more complex terms have served the same role. I have already mentioned two important examples: user involvement and recovery. The user activist and scholar Trivedi (2010) has observed that these are concepts ‘born out of service user/survivors[’] experiences, anger, hope, creativity and wisdom’, and intended to revolutionise the mental health care system. User/survivor activists and critical scholars warn that, over the past few years, these terms have been co-opted by mental health professionals and policy makers.
Take recovery for example. The idea of recovery in mental healthcare and policy seems to have originated in the user/survivor movement (Rose 2014). Within the movement, the term was used partly to frame structural problems facing people with diagnosed mental disorders or in severe emotional distress, and to highlight that recovery lay in addressing these problems rather than in – or at least in combination with – changing the sufferers. This entailed enhancing the individual’s say in treatment, exploring non-medical conceptions of and approaches to mental suffering, strengthening community membership and reducing stigma, as well as improving and safeguarding political rights (Pilgrim 2008; McWade 2016). The concept of recovery challenged conventional understandings and treatments of the suffering associated with mental disorder, which focused on individual problems and symptoms and how these could be ameliorated by intervening on the person. It was a way for individuals to link their suffering to the public issues pursued by the user/survivor movement, enabling them, in effect, to ‘cut loose’ from the medical frame and access the empowering factors of the movement.

Critics have charged, however, that as the idea of recovery has been taken up as a concept in mainstream mental healthcare and policy, it has been emptied of its critical, demedicalizing, and politicizing meanings (e.g. Morrow 2013; Pilgrim 2008). Recovery has been a buzzword in the mental healthcare policy reforms of British governments since the 1990s, signifying an ongoing transition to a more personalised approach to care that places an increased emphasis on the voices of patients (McWade 2016). As mentioned, charities and NHS trusts alike have supported or adopted the idea of recovery. But rather than recognizing the tensions between recovery and psychiatric approaches, these institutions have tended to represent them as unproblematically complementary, such that recovery might simply be appended to the existing mental healthcare system (Harper and Speed 2012). Indeed, the fact that two British psychiatrists, Mountain and Shah (2008), were able to conclude that there are no incompatibilities between recovery and the medical model – without mentioning the relationship between recovery and social or political context – is an indication of how far the meaning of recovery has drifted from its activist origins and instantiation. Mountain and Shah suggest that the principles of recovery are integral to the medical model that psychiatrists already employ and they primarily highlight points where existing practices could be strengthened. Mountain and Shah’s characterization of empowerment, which they identify as a core component of recovery, is also noteworthy. They state that empowerment is about: ‘Promoting self-control, self-management and personal responsibility and supporting patients to believe that they can shape their future’ (243). Strictly speaking, this conception of empowerment may not be incompatible with the collective power and political change sought by activists. But it evidently emphasizes the individual and personal change in a way that seems likely to steer users away from political action than towards it.

The individualization of recovery has been noticed and criticized by activists and critical scholars (e.g. Harper and Speed 2012; Howell and Voronka 2012). The implementation of recovery in parts of the NHS has entailed more practical interventions and aims than may have been common previously, such as helping people with mental disorders to develop skills for and to secure work and independent living. But focus has largely remained on the individual, her defects, and how medical experts can make her better (Rose 2014). Meanwhile, what Pilgrim (2008) refers to as the ‘forces of social exclusion’, that is, the ‘prejudice, stigma, and institutional discrimination against those
with mental health problems’ – which the activist instantiation of recovery brought into view – have remained peripheral in mental healthcare and debates about mental disorder. This seemingly has negative implications for the political agency of user/survivor activists as well as for others diagnosed with mental disorders. Using terms that recall my characterization of disempowering concepts, Harper and Speed (2012, 10) argue that recovery now ‘obscure[s] the social and political links between distress and structural injustice’. That is, what used to be an empowering concept has arguably become a disempowering concept.

For reasons I shall discuss shortly, it is not quite accurate to call recovery a disempowering concept, but its depoliticized instantiation does have disempowering effects. We can better understand these effects by considering the position of user/survivor activists in terms of epistemic injustice. Epistemic injustice refers to breaches of people’s status as knowers. The two types of epistemic injustice are relevant here: testimonial injustice and hermeneutical injustice. Testimonial injustice is when an individual suffers from a credibility deficit due to prejudices and stereotypes associated with her group identity (Fricker 2007, 27). Hermeneutical injustice refers to the injustice that affects a group when it lacks the hermeneutical resources – including concepts – to explain and communicate certain experiences to each other and others outside the group (154). Given that political agency requires personal credibility and hermeneutical resources, both forms of epistemic injustice are disempowering.

As Trivedi’s statement above illustrates, the activist instantiation of recovery functioned as a hermeneutical resource for users/survivors. Specifically, it functioned as a politically empowering resource that facilitated connections to other empowering factors. Perhaps most significantly, it helped to establish and maintain affiliations between a diverse range of individuals and groups (see also Woods, Hart, and Spandler 2019, 10–11). The depoliticization of recovery in policy and healthcare means that it no longer – at least not without clarification – reliably enables users/survivors to illuminate, for example, shared experiences of social exclusion and the importance of addressing this problem, either amongst themselves or to outsiders. Internally, some activists – notably, the Recovery in the Bin collective (2019) – have distanced themselves from the term, which they perceive as corrupted; others insist that it is useful despite its misappropriation (Morrow and Weisser 2012); and, presumably, still others are satisfied with its mainstream uptake. Hence, affiliations between them may begin to fray. It is in relation to external publics that the effects are likely to be most significant, however. The depoliticized mainstream meaning of recovery deprives user/survivor activists of an empowering factor that they had developed to express coherently and constructively the political dimensions of their suffering to doctors, politicians, and other stakeholders.

There is some room for disagreement within the frame of this mainstream meaning, such that recovery can mean somewhat different things to different people (Woods, Hart, and Spandler 2019). It may, for example, be tolerable for individuals to differ on whether recovery requires medication or behavioral change. These disagreements maintain that mental disorder and recovery are what, Mills (1959, 8–9) called, ‘personal troubles’ pertaining to ‘the character of the individual’ and ‘his immediate relations with others’. Meanwhile, many, though not all, meanings that would make or tie recovery to a public issue – such as substantively reforming psychiatry or addressing inequality – which demands political action and structural change seem intolerable. For activists to insist
on politicized meanings of recovery in the face of the expert-endorsed mainstream meaning is hard work and threatens to weaken their credibility; but abandoning the concepts means giving up a hard-won hermeneutical resource and empowering factor.

Users/survivors are not alone in facing this kind of problem. The appropriation of the user/survivor movement’s concepts to name what are arguably shallow reforms may be just one instance of the capacity of contemporary social and political systems to assimilate and neutralize radical critique (Boltanski and Chiapello 2005, 27). But unlike most political actors, user/survivor activists are acting from a position and drawing upon experiences that have already been medicalized. This means they have to politicize the ostensibly apolitical.

Despite anti-stigma advocacy, negative stereotypes about individuals with mental disorders continue to undermine the credibility of such people as knowers in the eyes of healthcare professionals and policy makers as well as in the eyes of sufferers themselves (Carel and Kidd 2014; Crichton, Carel, and Kidd 2016). They may, for example, be perceived as threats to other people or themselves. In 2014, a comprehensive survey in England found that 39 percent of respondents associated mental disorder with a tendency for violence (TNS BRMB 2015, 24). Such perceptions are clearly not conducive to political affiliations or credibility. The disempowering effects of stigma can also be subtler. Almost half the survey respondents apparently believed that an individual with mental disorders usually cannot ‘be held responsible for his or her own actions’. A further 40 percent associated mental disorder with the inability to ‘make simple decisions’ about one’s own actions (TNS BRMB 2015, 24). Testimonial injustice is, thus, a problem for people with mental disorders even before they have framed their experiences as public issues (or tried to), and one that is likely to follow them into political action.

So far, we have seen several ways in which the political agency of user/survivor activists and individuals with mental disorders, along with the empowering factors available to them, are undermined, for example, by psychiatric diagnoses and the mainstream appropriation of user/survivor concepts. However, what critics of psychiatry and – as Kurs and Grinshpoon (2017, 9) note – scholars of epistemic injustice often fail to recognize is the credibility of diagnosed individuals can be enhanced by psychiatric concepts and associated affiliations, tools, and institutions in certain contexts. As I shall elaborate in the next section, they can even be politically empowering.

6. The promises and pitfalls of ‘psycho politics’

The uptake of user/survivor concepts in the healthcare system – which in a sense medicalizes them – does not uniformly or necessarily disempower users/survivors. With respect to recovery, for instance, one could argue that its appropriation by the government and in the NHS has created new opportunities and resources for shaping mental healthcare and the rights of people who experience severe emotional distress or other symptoms of mental disorder. Its uptake gives activists a conceptual foothold in these institutions and healthcare debates. Some commentators even appear to see it as an opportunity for ‘re-inventing’ recovery, replacing its mainstream meaning with its original, radical political and demedicalizing meanings (Morrow and Weisser 2012). A more modest hope would be that by continuing to contest the concept, activists may be
able to complement the mainstream instantiation of recovery with concerns about political context. This is why I suggested above that it may not be appropriate to call recovery a disempowering concept.

A better, though still controversial, example of how the appropriation of a user/survivor concept in policy and healthcare can generate or strengthen political agency is user involvement. As mentioned, user involvement is another central tenet of the movement that has been implemented in mental healthcare policy, research, and practice. It is meant to give an institutional voice to individuals who have lived experiences of being on the receiving end of psychiatry, recognizing the role that these ‘experts-by-experience’ should have in providing and shaping mental healthcare. Since the 1990s, a series of policies established and extended formal requirements for user involvement across the NHS. Users/survivors were called to serve as members on hospital boards, support workers and consultants, research advisors and researchers. User involvement has received its share of criticism over the years. Doctors and users/survivors alike have complained that many user roles that have emerged over the years are simply figurehead positions (e.g. Trivedi 2010). Members and allies of the latter group have also charged that user involvement has marginalized the more radical voices of survivors in favour of the more reformist voices of users and has yielded little in terms of actual political power (McDaid 2010). Yet, some critics seem to underestimate the empowering potential of the spaces that user involvement has opened up, during a period when other spaces that may have served as sites for establishing affiliations, sharing experiences, and formulating public issues – such as inpatient facilities – have been disappearing. Even if hospital boardrooms do not provide opportunities to effectively contest broader issues within mental healthcare, they allow users/survivors to express critical opinions on issues to potentially receptive and influential professionals. Furthermore, as Tehseen Noorani (2013) observes, ‘rights-demanding activism [is] often conducted through service user involvement spaces’. Users/survivors in peer-support roles, for example, can and do sometimes facilitate the kinds of connections just mentioned. And partly by drawing on concepts such as recovery (Woods, Hart, and Spandler 2019, 15), they can do so as experts-by-experience, whose authority has, to an extent, been formally recognized by the very institutions they contest.8 I do not mean to dismiss the criticism of user involvement, which highlights how institutional compromises may hinder activism. I only want to underline that it is empowering with regard to certain matters.

But this is a crucial point; as Sedgwick suggests, psychiatric concepts can be politically empowering. A psychiatric diagnosis, for example, transforms subjective suffering into an intersubjective issue, something that people can talk about in shared terms and, potentially, politicize. Even if one rejects the way a diagnosis defines an experience, as user/survivor activists often do, psychiatric concepts can enable individuals to engage with others and articulate their suffering as a collective maladjustment to the injustices of the societies in which they live. This is a point that is obscured even in some of the more nuanced contemporary criticism of psychiatry. For example, in a recent paper, Svend Brinkmann (2014) proposes a distinction between different languages of suffering, including diagnostic language and political language. Diagnostic language, for Brinkmann, apparently encompasses the diagnostic categories of the DSM, as well as psychiatric aetiologies and treatments. Unlike some critics, he acknowledges that diagnoses may lead to ‘externalizations’ of an individual’s problems.
These can, in turn, empower the individual to act politically, through patient groups for example. Yet he insists that externalizing resources ‘come from outside the diagnostic language itself’, for instance, from political language – whose character remains vague in Brinkmann’s scheme. Although the distinction between diagnostic and political language partly resonates with some of the earlier reflections of this paper, it is overdrawn. Psychiatric concepts can indeed be externalizing and, hence, straddle Brinkmann’s categories. This is because psychiatric concepts are enmeshed in a network of affiliations, spaces, tools, laws, institutions, and other concepts. These and other connections are what give psychiatric concepts their authority; they are the reason psychiatric concepts have such a powerful impact on us. For individuals who become the targets of diagnoses, these connections are in some cases empowering and in others disempowering. In the UK and elsewhere, a diagnosis of mental disorder entitles the individual to services from institutions, which are subject to ongoing political debate and visible political governance. When these institutions fail the individual, she may find the resources for understanding and acting upon this failure as a public issue through the connections that her diagnosis has entangled her in. This includes user/survivor groups of course, but also factors that are part of the medical system, such as regulations stipulating care standards, treatment records, medical staff, and so on. By gathering with others in a space where they will be heard and seen, and state that they have a diagnosed disorder for which they have been denied proper treatment, medicalized individuals are raising issue of shared concern through institutional channels and collective action – that is, they are exercising political agency. Brinkmann (2014, 642–643) might object that what I have described here entails political language in addition to diagnostic language; he would be right. My point is that some apparently political concepts – like the right to healthcare – and other potentially empowering factors are partly constituted by psychiatric concepts and authority. This means that the same factors that make the act of diagnosis so powerful can make the actions of the diagnosed powerful as well.

Notwithstanding the potentially empowering effects of psychiatric concepts and, by extension, medicalization, Sedgwick’s ‘psycho politics’ has its pitfalls. Sedgwick urged the politicization of ‘medical goals’, albeit in what he hoped would be an increasingly socialized healthcare system. But the range of experiences and issues that one can credibly raise within the context of the medical system or frame as medical goals seems relatively narrow. Doing so successfully might empower activists to shape the healthcare system to an extent. However, it may also put an upper bound on their political agency, by constraining the range of empowering factors available to them. We have seen, for example, that while there are many narrower and ‘dimmer’ spaces – ranging from social media groups to hospital board rooms – within which user/survivors can explore and act on experiences and issues, wider and ‘brighter’ spaces like the news media have had little room for them. Similarly, the psychiatric concepts and affiliations that user/survivors draw on may be empowering when they raise certain issues. Yet these factors also make user/survivors and their political actions particularly vulnerable to medical expertise, and we have seen examples of the kinds of powerful resistance from psychiatrists and pundits as well as governments and healthcare systems that can be engendered by user/survivors’ attempts to politicize mental disorder.
Beyond this, there is of course also the concern at the heart of much contemporary criticism of psychiatry and King’s earlier words about maladjustment to injustice, namely, that most people who have been diagnosed with a mental disorder been diagnosed will simply adjust themselves, with the help of therapy and medication, to the injustices that may have caused their medical suffering in the first place, never considering the possibility of political action. Sedgwick dismissed this concern: ‘It is as though people believe there is only a finite pool of grievances for radicals to work with’. This, he suggested, is quite absurd, ‘for no matter how many maladjustments may become adjusted through expert techniques, the workings of capitalism will ever create newer and larger discontents, infinitely more dangerous to the system than any number of individual neuroses or manias’. Such an appeal to what Arendt (1961, 61) would call the ‘iron law’ of ideology – which in Sidgwick’s case was unabashed Marxism – is suspect to begin with. But even if we could take it for granted that capitalism will continue to produce new and non-medicalized forms of suffering and other experiences that can fuel political action, Sedgwick’s argument has a troubling implication. It suggests that we do not have to worry about the disempowering effects of the medicalization, because people will always find the resources for political action eventually. Yet, that might well be at the cost of individuals whose suffering is being medicalized now, whose complaints about discrimination and marginalization are met with diagnoses and medications – individuals who could have added their power to the user/survivor movement, or indeed some other political action, and perhaps changed the world for the better today.

7. Conclusion

This paper has examined the factors that shape the political agency of user/survivor activists. I began by outlining an Arendtian framework for thinking about political agency, highlighting five dis/empowering factors that may enhance or diminish the individual’s capacity to act in concert with others to shape or respond to public issues: affiliations; spaces; things and tools; laws and institutions; and concepts. Since concepts seem particularly important in relation to medicalization, I elaborated on the difference between empowering concepts, which reveal the possibilities for political action, and disempowering concepts, which obscure them. I then proceeded to survey the psychiatric user/survivor movement. This movement consists of groups that constitute and provide empowering factors for individuals who reject psychiatric understandings of their mental suffering. These groups offer access to political affiliations, spaces, and concepts, i.e. empowering factors that can help people to articulate their suffering as public issues and act in concert to address them. Yet we have also seen that before and after joining any such group, individuals diagnosed with mental disorders face disempowering factors. These people are vulnerable to prejudices about mental disorder, which, for example, impeach their capacity for reason and responsible action. Relatedly, users/survivors may struggle to find concepts and other empowering factors that permit them to understand and act on their medicalized experiences politically. Concepts that do frame their experiences as public issues and enable them make demands on the government and the healthcare system have in notable instances been appropriated and depoliticized by these institutions. However, I have also argued that neither the appropriation of user/
survivor ideas nor psychiatric diagnosis necessarily diminishes political agency. It can also be empowering. A diagnosis and psychiatric language more generally can enable individuals to make more effective and collective demands on healthcare services and the people responsible for them, as well as businesses, schools, governments, and other institutions that are perceived as responsible for the health of some communities.

What does this say about how the medicalization of suffering affects political agency more generally? (Fisher 2009) has argued that medicalization has led to what he calls ‘reflexive impotence’, whereby individuals ‘know things are bad’ but also ‘know that they can’t do anything about it’ – at least politically. Yet user/survivor activism indicates that the medicalization of their suffering may in fact enable individuals to frame their experiences as public issues and act on them in concert with others. Of course, this is different from saying that medicalization generally leads people to understand their experiences as amenable to political action; more likely, it leads them to visit a doctor, take a pill, and try to move on with their lives. But then again, few experiences actually do lead us to take political action. The more pressing concern is that even though a medical framing might increase the political agency of individuals in certain instances, some public issues probably cannot be adequately expressed in psychiatric or medical terms at all. This raises an important question: in a society where political matters may increasingly have to be framed in medical terms or another expert language to be heard, how will suffering and disadvantaged people be able to participate effectively in politics? We might have seen one possible answer to this question already in recent elections and referenda, as politicians ostensibly speaking for the working class have declared that people have ‘had enough of experts’, a reaction which is hardly without its own dangers.

Notes

1. The term ‘mental disorder’ is controversial among psychiatric service users/survivors, many of whom instead prefer to talk about mental or emotional ‘distress’. In the context of this paper, I am deliberately using ‘mental disorder’ in order to emphasize that I am talking about people who have been diagnosed/labelled through the mental healthcare system. I am grateful to the anonymous referee who suggested this clarification.

2. An important recent work on the user/survivor movement is Mohammed Rashed’s Madness and the Demand for Recognition (2019). Our respective investigations have different but complementary foci. Whereas the concept of political agency guides my analysis, Rashed’s guiding notion is recognition. His objective is to justify philosophically that mental disorders can be a basis for identity and that user/survivor activists’ demand for recognition on this basis has legitimate normative force. By contrast, my own concern could framed as how and why user/survivor activists’ demands with respect to recognition or other issues obtain or fail to obtain significant uptake and support their political agency and empowerment.

3. Of course, individuals have been and continue to be deprived of formal political rights through what in Britain is called ‘sectioning’.

4. I elaborate on this definition of political agency further in Degerman (2019).

5. Arendt herself occasionally problematized the political use of psychiatric diagnoses, framing the phenomenon as an example of a ‘comfortable, speculative or pseudo-scientific refuge from reality’ (1972, 130-131; see also 1992, 25–26). More broadly, she seemed more concerned with the political implications of psychology (e.g. 1998, 322, 2005b; 1992). For a discussion of Arendt’s views on psychology and psychiatry, see Norberg (2010).
6. For a comprehensive historical survey of the user/survivor movement in the Britain, see Crossley (2006).

7. The articles found in the ProQuest research were: Adams (2015), Ahuja (2006), Allan (2006, 2007), Baker (2006), Beresford (2011), Blair (2006), Brand (2007), Brockes (2013), Browne (2011), Daily Mail (2013), Daly (2013), Duffy (2013), Friel (2011), Hilpern (2007), Hughes (2016), Jackson (2008), Kirsch (2007), Lewis (2008), Linklater (2007), Maddock (2012), Meltzer (2013), O’Hara (2009); O’Hara (2011)), Parker, Harper, and Webster (2008), Rahtz (2014), Sanders (2016), Shortall (2009), Smith (2009), Sunday Times (2012a, 2012b).

8. My reflections on the empowering effects of user involvement draw on Noorani’s (2013) empirical research and analysis.

9. These points resonate to an extent with Nikolas Rose’s (2006) idea of ‘biological citizenship’; however, I believe Rose is too blithe about the disempowering effects of psychiatry and medicalization.

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