Service user involvement, authority and the 'expert-by-experience' in mental health

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Service user involvement, authority and the 'expert-by-experience' in mental health

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This article re-examines the politics of engagement of the UK mental health service user and survivor movement by focusing upon the mental health 'expert-by-experience'. Using qualitative data, I illustrate how the service user and survivor movement is able to draw upon an *experiential authority* that is rooted in practices of self-help and peer-support. I do this by bringing an experimentalist reading of self-help and peer-support practices into dialogue with a model of *traditional authority*. As such, the personal can be linked up to the political in ways that emphasise the value of self-help and support practices *as* forms of political participation, while highlighting modes of engagement that are predicated on the capacities, rather than the needs, of the movement.

Keywords: experiential authority; positive critique; experts-by-experience; mental health; self-help; service user involvement; survivors

Perhaps we will accord to the so-called schizophrenics who have come back to us, perhaps after years, no less respect than the often no less lost explorers of the Renaissance. Laing (1967, p. 107)

Introduction

This article connects the broadly 'therapeutic' effects of self-help and support practices with the political capacities of the service user and survivor movement in mental health. I trace a history of service user involvement mechanisms in contemporary mental healthcare in the UK, and use interview data to illustrate some of the political responses to these forms of governance. I then draw upon political theory to develop a concept of *experiential authority*, in order to better grasp what is distinctive about the idea of 'expertise-by-experience' in mental health. I argue that we need to appreciate the *positivity* of the authority that is being produced in the service user and survivor movement, by connecting the capacities and techniques developed in the practices of living through distress and working upon experiences of mental distress in self-help and support group settings to the political potential of the emergent actors. I attend to certain capacities and techniques produced within self-help and support group practices for the purposes of intervening in one's own distress, that are then utilised by service users and survivors when engaging with governmental mechanisms, healthcare professionals and the broader public on questions of what we mean by mental distress and 'madness', how we

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should deal with it and how we might challenge stigma in mental health. This article therefore encourages attending to self-help and peer support spaces for working on mental distress as sites for developing new tools of political engagement, rather than accepting the dichotomy that self-help and support practices are proper to questions of health, while advocacy and campaigning are matters for activism. At the same time, it contributes to emerging conceptualisations of experiential authority (see also Dawney, 2013 and Millner, 2013).

I draw upon qualitative empirical data from a three-year study of the capacities of the mental health service user and survivor movement in the UK, conducted between 2008 and 2011, and include interviews with local and national members of two self-help networks – Bipolar UK[1] and the Hearing Voices Network (HVN)[2] – and interviews with one local survivor activist and one local government mental health commissioner. My aim is to use the interviews to illustrate the argument of the article, rather than provide a systematic or comprehensive overview of the key themes found in the interview data.

Section I: service user involvement and survivor activism

Over the last 20 years, mental healthcare in the UK has proclaimed the need and value of service user involvement. Its importance is evident in government policy (Department of Health [DoH] 1999, 2000, 2001, 2005, 2009, 2011, Lewis 2009), emphasising how service users are experts-by-experience with a privileged understanding of their mental distress, what they need for their recovery, and how current service provision is, and is not, providing it. Beresford (2002) suggests service user involvement has emerged out of two different rationales for participation – one consumerist, the other democratic. The former claims that greater efficiency, efficacy and effectiveness will result from appropriately-placed service user feedback mechanisms. The latter, democratic approach, often framed in a rights discourse, views user participation as a form of self-advocacy. Pilgrim (2005) suggests a similar if more polemic distinction, between 'co-opted' service users on the one hand and activists or 'survivor' service users on the other. The term 'survivor' refers to those who have survived not only their mental health difficulties, but also experiences of psychiatric services, and/or the accompanying general social exclusion (Ibid., p. 19). Pilgrim thus describes a tension between user involvement as a *management resource* and as a *manifestation of protest*:

> On the one hand 'experts by experience' have been a part of a new social movement of disaffected service users attacking psychiatric theory and practice. On the other hand, the oxymoron of a 'lay expert' has found its time and modern health and welfare bureaucracies now emphasise consumerism as a source of quality improvement. (Ibid., p. 17)

For the sake of clarity, this article will refer to the service user and survivor movement as being distinguishable, on historical and teleological grounds, on the one hand by a 'service user' component, and on the other, by a 'survivor' or 'activist' component. Service user spaces are used to measure and evaluate service provision, using feedback to improve future service delivery. Survivor/activist spaces promote user-led service development, often reframing the problems faced by mental healthcare governance and the mainstream solutions to these problems. While service user

and survivor/activist spaces overlap enormously in practice, the distinction is helpful in indicating divergences in their respective histories and aims.

The historical context

We can trace a history of service user involvement in statutory policy and guidance from when the rhetoric of 'user involvement' became a central part of NHS policy during the establishment of the Community Health Councils in 1973. This continued through the proliferation of New Public Management principles and the growing importance of measures of satisfaction in the 1980s (Tait and Lester 2005). The 1990 NHS and Community Care Act established a formal requirement for service user involvement in service planning. From 1997, patient and public involvement were a central tenet of New Labour's NHS modernisation agenda (DoH 1999), and the *NHS Plan* (DoH 2000) was committed to creating a patient-centred NHS with user needs at the centre of service design and delivery. Section 11 of the Health and Social Care Act (2001) required all NHS organisations to engage users in planning and evaluating services, as well as in decision-making on issues of treatment. The *Expert Patients Programme* (2001) was hailed by England's chief medical officer as 'ushering in a new era of opportunity for the NHS' (Donaldson 2003, cited in Greenhalgh 2009, p. 631). In 2003, the New Labour government appointed a 'Patient Tsar' to advise on improving service user experience, and to publish measures to increase patient choice across the NHS (DoH 2003). At the same time, the Commission for Patient and Public Involvement in Health was established in 2003, whose functions were transferred to Local Involvement Networks in 2008, which are currently being replaced by local Healthwatch organisations. The guidance on the *Care Programme Approach* (DoH 2008) and the *New Horizons* (2009) strategy under New Labour further supported user involvement. The most recent strategy, written by the Conservative-Liberal Democrat coalition government, *No Health Without Mental Health* (2011), appears to have relied less on the notion of 'involvement', while emphasising 'choice', together with a focus on active service user and carer involvement as well as the fruits of market competition. This perhaps indicates the assumption on the centre-right of the party political spectrum that market-driven choice is tantamount to involvement; how exactly this pans out is yet to be seen.[3] Nevertheless, this brief history illustrates how the discourse, mechanisms and processes of service user involvement have become increasingly integrated into all levels of decision-making and service delivery over the last 40 years.

Turning to the survivor movement, the term 'survivor' emerged when a group of individuals in the early 1970s began campaigning and protesting against the treatment of those in the mental healthcare system, while maintaining opposition to the dominance of medical interpretations of their experiences (Tait and Lester 2005). As a grass-roots movement, it was accompanied by an intellectual critique against biomedical models of illness and coercive measures of control, in what became known as the 'anti-psychiatry' movement (e.g. Laing 1960, Goffman 1961, Cooper 1967, Szasz 1974). However, the history of mental health activism can be dated far further back, to at least 1620, when inmates at the Bedlam asylum petitioned for their rights (Weinstein 2010). In the contemporary period, from national organisations such as Survivors Speak Out (formed 1986) and the United Kingdom Advocacy Network (formed 1990) to local survivor organisations today, their approach to involvement has been more overtly oppositional toward models of

illness and care than the service user involvement movement, often drawing upon human rights discourses. Rose (2001, p. 67) claims that the user movement in the UK began when individuals placed demands to be listened to as users at the World Health Organisation conference in Brighton in 1986, and again at the Common Concerns conference in Brighton two years later. All of the different, imbricated difficulties with service user involvement have nourished advocacy groups that resist biomedical dominance and coercion in the name of survivor activism.

What unites both the consumerist subject position of service user and the oppositional subject position of survivor, is that they are granted authority by virtue of their experiences of mental distress and/or of service (*ab*)use, and seek progressive developments in the treatment, perception and governance of the experiences of mental distress.

Section II: engagement and contestation: historical transformations and current dilemmas in a local context

There is a wealth of literature detailing the pros and cons of service user involvement, and the frustrations experienced by the activist component of the movement (see e.g. Wallcraft *et al*. 2003, Tait and Lester 2005, Kalathil 2008, Greenhalgh 2009, Lewis 2009). Rather than summarise these findings, I will turn instead to a local area to contextualise some of the issues concerning the politics of resistance, using excerpts taken from interviews with a local mental health service commissioner and a local survivor activist.

At a local level, activist groups often attempt to influence service provision through campaigning, lobbying and advocacy, and service users are asked to sit on fora to advise providers and commissioners at operational and strategic levels. There are current and ex-service users who are recruited to service user representative posts within services, and public health-funded roles for community development workers, whose role has been to engage with 'hard-to-reach' communities (DoH 2005). Moreover, some local commissioning teams have developed service user-led service evaluation schemes, involving interviews, questionnaires and visits combined with other data in order to conduct their own user-led evaluation of services. A body of literature on 'user focused monitoring' has grown around such user-led monitoring and evaluation practices, and is used to inform the development of these systems and processes (Kotecha *et al*. 2007).

Many within the local survivor movement seek new spaces for collectivising. Some in the survivor community claim that the widespread existence of psychiatric hospitals until the 1980s at least provided spaces for connection, sharing experiences and building a sense of community and activism. They suggest that the turn towards 'care in the community' has had the effect of reducing the number of these kinds of spaces, including drop-ins and day centres that are also not considered progressive *qua* socially inclusive. One activist identifies in this a mentality of divide-and-rule:

> I remain convinced that one of the reasons for closing down all the day hospitals and the day centres is actually 'divide-and-rule'. Because people don't meet each other. In the day hospital you sit there and you have coffee with people, and you're going for a group, and then you talk to people afterwards and you have lunch whereas now, mostly it's done in your own home – it's privatising the experience of being a patient.

> If you do go to these public places, the resource centres, you go and see *your* worker, or you go to *the* group, and then you go home. And you don't have any contact with anybody else. So you can't share your experiences, you can't raise each other's consciousness, and you can't offer mutual support. (Interview with local activist 2011)

The local activist argues that all spaces of sharing provide the potential for the politicisation of its inhabitants, and laments the lack of spaces available for building community today. Like many others, she also problematises the lack of willingness to identify as 'mad' or a 'service user' or 'survivor', which she takes to be a prerequisite for addressing the stigma associated with mental health problems (Ibid.). Questions that emerge for mental health activists include whether and how to continue to struggle to build relations of community, where to look for new strategies of resistance, or indeed whether to look for new strategies of resistance through reconceptualising what is meant by 'community' in the first place.

A local commissioner agrees that such changes are taking place, but does not seek a return to healthcare models that incorporate collective spaces. He suggests that providers and commissioners of mental health services over the past 20 years have produced a dependency culture, whereby services can infantalise users by moulding them into feeling and acting 'like spoilt children', while 'pedalling the lie of service user "empowerment"' (Interview with local commissioner 2009). He suggests that the ineffectiveness of mental health service user involvement is indicative of a larger and historically drawn-out phenomenon (Ibid.) whereby a radicalism once found amongst self-described 'survivors' has been replaced by the reactive subject position of 'service user', which does little to advance discussions of mental health service provision. He suggests that what is needed is 'light-touch' service user involvement, to go hand-in-hand with increasingly light-touch services. This would allow people who use mental health services to no longer identify themselves so fully with the category of 'service user', allowing them to move on in their lives. Meanwhile, the commissioner suggests, service improvement spaces would be more productive without the reactivity of service user representatives 'blocking decisions at every stage' (Ibid.). The commissioner claims that the survivor movement of the 1970s and 1980s held a mirror up to services and exercised a power of parody much like a court jester (Ibid., cf. Foucault 1965). By contrast, he views the service user movement as reactive, often opposing any attempts to improve services and at the same time reinforcing its own passivity in the face of change (Ibid.). Thus the proliferation of service user involvement spaces has itself become the problem, and for the local commissioner, in line with recovery and social inclusion agendas, an improvement would be to develop light-touch user involvement mechanisms involving fewer and less-involved spaces, utilising technologies of feedback integrated into the service delivery itself.

The narratives of the local activist and the local commissioner share many overlaps, even if their prescriptions differ along broadly communitarian and neo-liberal lines respectively. The local activist describes how the survivor movement of the 1980s was made up of those who were unhappy with their experiences of the mental healthcare system but did not think of themselves primarily as *users* of services:

> We called ourselves survivors; we didn't call ourselves service users! We were survivors of the system, we were survivors of mental health problems. (Interview with local activist 2011)

She charts what she describes as the 'appropriation' of the survivor movement by service user spaces. She suggests that the energy of the movement has been redirected into service user involvement:

> There was this temptation of people – when we first started being asked, if we [would] be interested in getting involved in planning this service, looking at how that service was going, and looking at issues here and issues there. And it's become so that the user movement has actually now become part of the structure. And to the extent that within our Trust, if you want to have any say, you're effectively an employee of the Trust. And that's where the energy is, where an awful lot of people who use the services or have used the services get taken up. (Interview with local activist 2011)

As user involvement spaces opened up within service provision, the local activist describes how the emphasis of the service user and survivor movement changed, from looking at the broader effects of distress and mental healthcare provision to considering the immediate conditions and experiences that service user representatives saw around them:

> … it's been very difficult to get people to think about anything other than very min-ute, day-to-day functioning within how the hospital functions, and how the secondary sector functions. It's very hard to get them to think on a wider political level about services in general, or the experiences of people with mental health problems in the world. It's very difficult. People don't want to do it. And I just think that's where all the energy's been sapped to. (Ibid.)

This focus of energy on immediate problems detracts from addressing broader issues concerning mental distress, and puts that energy into focusing on the scale of the local and the immediate. Moreover the local activist regards this problem as exacerbated by the fact that most distress occurs outside the mental health system (Ibid.). If 'participation' were framed as a broader set of issues than those limited to service improvement, participation would not be confined to the individuals that the local activist points out are (understandably) mostly concerned with their day-to-day experiences of service delivery.

Nevertheless, on the service delivery level, the local activist suggests that ser-vice user representation on staff and management meetings allows service users to air critical views, even ones that junior staff themselves may have but are too cau-tious to voice. They can do this precisely because they are not employed. As such, this capacity is threatened by processes that transform service user involvement roles into subject positions more similar to those of employees (see e.g. Carmel and Harlock 2008), through various NHS Trust and service governance mechanisms. For example, the local activist explains,

> … [service user representatives] have to undergo the Trust trainings, and then they have to go on the Trust database, and then the Trust will decide who they want to attend meetings, or asked to attend panels. So you have to become quite tame in … order to take part in things. (Ibid.)

Attempting to typologise correlations in the agents and problems of participa-tion, Lakeman *et al.* (2007) describe the service user and survivor movement as distributed across a hierarchy of *authority*. Outlining a pyramid with three tiers or levels, at the bottom they place the vast majority of service users, who have the

most legitimate claims to being described as service users, but the least authority as service users. For these people, Lakeman *et al.* explain that their 'authority is undermined by judgements of diminished decision-making capacity' (2007, p. 15). They place so-called 'professional service users' in the middle row of the pyramid, whom they describe as sometimes unpaid and sometimes paid, and who work for service user groups or mental health service providers. Lakeman *et al.* suggest that these people:

> … need to have some commitment to the ethos, legitimacy and authority of the employing organisation which extends some of its authority to the employee, and the employee enhances the legitimacy of the organisation. (2007, p. 15)

Using the example of asking service users to be part of interview panels, Lakeman *et al.* argue that organisations carefully moderate service user authority, in case they claim more than the organisation is willing to grant them the power to claim (Ibid.). At the top of the hierarchy are what Lakeman *et al.* refer to as 'celebrity or corporate service users' (Ibid., see also Barker and Buchanan-Barker 2008), who are often charismatic and very articulate, and who use terrible stories of adversity to convey their journeys of transcending distress and sometimes even service use altogether. However, Lakeman *et al.* criticise the co-option of these celebrity service users into consumerist processes of endorsement and reinforcement of the status quo, and call upon them to 'return to their roots' in activism, demanding of them,

> … a collective voice demanding social transformation steeped in human rights and equality. (Ibid., p. 16)

In summary, as spaces for participation change, some see a need for more collective spaces to be nurtured, while others see service user involvement as already too large and ineffectual precisely because it has been so heavily emphasised over the last two decades. And yet others call for a return to activism, as service user involvement has co-opted the 'survivor movement'. The last claim may not necessarily mean a return to collective spaces, but to new ways of harnessing an authority steeped in service user and survivor experiences. Ideas of expertise-by-experience seem to do precisely that, but as the local activist points out, are also co-opted by a consumerist logic, becoming precisely the reason for inviting service users onto meetings and panels and so on, while remaining uncritical of ultimate goals such as choice and efficiency (Interview with local activist 2011).

Throughout their article, Lakeman *et al.* (2007) make reference to the link between experience and expertise, without theorising the conjunctive term, 'expert-by-experience'. They note, for instance, that:

> [t]he authority of the celebrity often extends well beyond their knowledge, expertise or experience. (Ibid., p. 15)

The relation of these terms is crucial to their argument, and yet points to a general gap in the academic literature on the politics of the service user and survivor movement. In the following section, I will attempt to develop a conceptual framework for explaining the links between knowledge and authority, experience and expertise.

Section III: rethinking authority

What is experiential authority?

Lakeman *et al*.'s (2007) analysis is interesting because it illustrates the diversity of experiences of service user involvement: the differences between those at either end of the authors' three tiers of service user power, for instance. There are, however, limitations to their analysis. In relation to celebrity service users, they conclude that:

> … they pose no real challenge to the legitimacy or authority of psychiatric institutions, and health professionals can smugly congratulate themselves on their liberal open attitudes to service user involvement while carrying on business as usual. The more successful celebrities will be those who concur with a medical view of illness rather than seriously challenging prevailing views or practice. (2007, p. 15)

There are many examples today of (ex-) service user activists, such as prominent members of the HVN, or controversial clinical psychologist Rufus May,[4] who are well known critics of medical perspectives. The elision of these voices may stem from Lakeman *et al*.'s reduction of 'celebrities' within the service user movement to its consumerist component, thereby sidelining consumerism's sibling which, as Beresford claimed above, is a rights-demanding activism, often conducted through service user involvement spaces but by those who call themselves survivors rather than service users.

The literature that considers the complex issues concerning service user and survivor movements in terms of authority and power (e.g. Coleman 1996, Lakeman *et al*. 2007) tends to do so in negative terms, either as resisting the power and the authority of the medical model or as resisting the force of mechanisms of coercion and restraint. What is needed is an analysis of the *positivity* of the authority that is being produced through service user and survivor groups, an authority that emerges from living through and working on experiences of mental distress. I suggest that it is vital to locate the political potentials, challenges, and resources offered by self-help and peer support practices. In turning to a concept of experiential authority, I shall now try to flesh out one way of exploring the term 'expert-by-experience' in mental health. It is clear from the various descriptions of experiential knowledge within self-help practices that there is something about experience itself that is worth listening to.[5] That is, self-helpers come to trust their memories of experiences of distress, letting experience act as a guide by deferring to it in times of uncertainty. It is in the nature of experience that it teaches truths not accessible through other forms of knowledge, such as protocols or textbooks. Indeed, past experiences come to offer promises of experiences to come. In these ways, experiential knowledge acquires its own authority. Such phenomena prompt a theorisation of the authority of those who are experts in engaging with their experiences and in particular their distressing experiences.

In the following three sections, I develop a reading of the 'experential authority' of the expert-by-experience, by opening up a conversation between a model of traditional authority and the idea of self-help practices as experimental spaces. In particular, I will use the authority of veteran group members over newcomers as an analogy for the nature of an experiential authority that operates between self-help groups and their various publics.

Weber (1958) offers the most well-known sociological analysis of models of authority by way of describing three systems of rulership or 'imperative coordination' – charismatic, traditional and legal-rational. These models of authority all entail particular relations between the authoritative figures and their subjects. Each entails its own affective components, including particular *experiences of authority*. Here I am interested in the inverse term – the *authority of experience*. In theoretical models of authority, from Max Weber to Hannah Arendt, there is no clear way of theorising a specifically experiential form of authority, such as that produced through self-help groups and support groups. One strategy for incorporating experience into a concept of authority is by appeal to the role of tradition in 'passing down' the authoritative relation; another is to appeal to derivative forms of authority, such as where the expert-by-experience is granted authority through the legal-rational authority of government policy-making.[6] Certainly, self-help and support group researchers have not adequately theorised the authority produced within and through these practices. In a rare exception, Borkman (1999) describes how self-help groups,

> … in questioning the adequacy and effectiveness of professional knowledge or practices, are experiential authorities with an alternative knowledge base and perspective. (Ibid., p. 69)

However Borkman's formulation of experiential authority, in terms of alternative critical knowledges, does not address a crucial property of the authoritative relation, whereby authority must be granted by its subjects if it is not to be domination (Arendt [1954]1993). That is, subjects to authority must understand and accept the truth-claims of authority, regardless of whether the subjects acquiesce to it at any given time.

Authority for Arendt is a form of positive power; advice with a force to be heard amongst its subjects. This means that authority is not simply a function of language or context, nor is something authoritative simply because individuals choose to view it as authoritative. Rather, authority exists and endures in the world. Arendt writes of authority that,

> Mommsen called it 'more than advice and less than a command, an advice which one may not safely ignore,' whereby it is assumed that 'the will and the actions of the people like those of children are exposed to error and mistakes and therefore need 'augmentation' and confirmation through the council of elders.' The authoritative character of the 'augmentation' of the elders lies in its being a mere advice, needing neither the form of command nor external coercion to make itself heard. (1993, p. 123)

This kind of advice-giving is premised on the authority figure having access to certitudes beyond the knowledge of the subject who grants the authority. The voluntary nature of the granting of authority by the subject of authority ensures it is distinct from coercion. This suggests that authority thus conceived demands trust in the authority figure's access to a truth beyond one's limited knowledge. In this way, it is not akin to mere persuasion, where the gap between knowledge and truth can be closed through explication (Ibid., p. 92–93). I suggest that authority posits a necessary gap between the knowledge of a subject and the claims to truth of the authority figure, a gap which demands trust. The authoritative relation exercises a positive

power of influence, because the authority figure is understood to speak on the basis of knowledge beyond that of its subjects (see Blencowe 2013; Dawney, 2013).

I argue that there are important ways in which mental health expertise-by-experience extend and/or differ from the tradition-based conception of authority so far outlined. Arendt emphasises transcendence in her concept of authority. She also claims that authority no longer exists because we have lost the connection to the past that was a prerequisite for authority in the Roman *civitas*. In the following three sub-sections, I will first suggest that experiential authority is produced through an interplay between oneself and one's distressing experiences, and as such is borne out of truths immanent to experience rather than transcendent to it. Secondly, I will argue that authority is maintained by producing a style of reasoning particular to it, which is not necessarily done through appeal to a pre-existing tradition. Rather, the collective memory of communities of self-helpers builds a historical record of self-experimentation through the production of techniques as forms of engagement, and this serves the same function as the concept of tradition in preserving and transmitting the authoritative relation. Both of these sub-sections concern the production and endurance of authority between members within groups. The final section shifts gear from the veteran-newcomer relation to the group-public relation, and addresses the ways that this authority is recognised by groups' publics. In this final section I will show how the novel forms of communication produced out of self-help practices allow publics to grant authority to the expert(s)-by-experience, by affirming the rationality (or sense-making) of their experiences of distress.[7] This allows us to bear witness to the relevance of 'their' expertise as an advice that 'we' cannot safely ignore.

Self-authorisation: experimentation and problematising judgement

Traditional models of authority tie it to a constitutive 'outside', as the ground of truth, which is beyond the direct reach of those who consequently submit to the figure of authority. The authority figure then claims to speak on behalf of this outside, which offers a ground from which one is able to pronounce judgement (Blencowe 2013). How can we understand this outside in relation to self-help practices? Of holders of such expertise, Borkman (1999) writes:

> A [mature] member of a self-help/mutual aid group has a wider range of experiential knowledge, understanding, and wisdom than a … newcomer or loner who has never problem-solved his [*sic*] condition with any knowledgeable peers. Neither the newcomer nor the loner would know the variety of ideas and feelings on various aspects of the condition, the various trajectories of problem solving and resolution, and so forth. In addition, the trap of dogmatism is less likely among those who have heard many people's stories of how to resolve the common problem. (p. 162)

This process requires the building up of trust, which is a necessary condition of the production of the truths that constitute the experiential authority of self-helpers. Indeed, the facilitator of a local self-help group refers to these two terms when describing how self-help groups are:

> … spaces for the development of truthfulness and trust in … the discovery of a new relation of the self to the self. (Interview with self help group facilitator 2009)

Both the HVN and Bipolar UK insist that everyone has their own perspectives on their mental distress, encouraging an engagement with the distress through experimental projects of self-understanding.[8] Many of the self-help techniques produced through self-help group meetings enact an exploration concerned not so much with escaping, rejecting or opposing the experience of distress, but working with it and on it, deepening the experience and understanding it better rather than judging it on the basis of outside or pre-given criteria (e.g. see Coleman and Smith 1997, Smith 2001, Martin 2006). The authority over newcomers to groups that emerges from this is not then based in some outside or foundational referent, but is produced through the sharing of experiences and techniques for working on experience that transform the boundaries of our knowledge. These produce capacities, through layered experiments that add a weightiness to claims to 'know'.

This kind of experiential knowledge might be considered in terms of Deleuze's distinction between 'combat' and 'judgement' (Deleuze 1997). Here, eschewing judgement is not about refraining from acting. On the contrary, Deleuze describes the power of judgement as the applying of criteria that pre-date, and are unmoved by, the existence of whatever is to be judged. Because judgement requires a regime of evaluation, he explains,

> If it is so disgusting to judge, it is not because everything is of equal value, but on the contrary because what has value can be made or distinguished only by defying judgement. (Deleuze 1997, p. 135)

Deleuze's converse quest is for us to engage with what agrees with us, to join with forces that increase our power and avoid those that decrease it. This is combat, and,

> … it is combat that replaces judgment … The combat against the Other must be distinguished from the combat between Oneself. The combat-against tries to destroy or repel a force … but the combat between … tries to take ahold of a force in order to make it one's own. The combat-between is the process through which a force enriches itself by seizing hold of other forces and joining itself to them in a new ensemble: a becoming. (Ibid., p. 132)

In introducing his concept of *becoming*, Deleuze allies this form of encounter with the philosophy of Spinoza (Ibid., p. 135). Certainly, combat has a synergy with the processes of engaging with, differentiating and understanding experiences that are developed in self-help practices. While judgement comes from the outside of thought and applies to experiences criteria that themselves have been unmoved by those experiences, combat allows us to approach the idea of immanently producing such an outside: a moving (set of) boundaries that are transcended and replaced at once.[9] This is then not a pugilistic sense of combat, but akin to transforming oneself through the taming of forces that interact with(in) oneself. It is a cultivated reflexivity of becoming as attuned to one's own internal diversity as possible, all the while knowing that the current state of affairs could change at any moment.

Deleuze's distinction between judgement and combat allows us a certain conceptual space for understanding the practices of working with and through distressing experiences. This is not to say that service users are 'non-judgemental'. Indeed, the difficulties of service user involvement described above by the local commissioner suggest that service users do judge in their roles within governmentalised spaces.

Moreover, collective spaces such as those described as lacking by the local activist are prone to a judgemental resentment, even *ressentiment*. The argument I am putting forward is that the expertise-by-experience of those who have worked upon their distress allows them to develop capacities through practices of ethical self-work for deferring or frustrating judgement.

Culbert (2008) offers a contrasting perspective on the 'problem of judgement'. She sets up the problem of judgement as one of how to understand the ways that under 'conditions where shared criteria for determining what is good or just are lacking, we judge, and not just for ourselves but for others' (2008, p. 3). Culbert emphasises the role that time plays in judgement, encompassing the Arendtian themes of judgement as both a closure and a beginning, as well as the importance of timing and preparedness in the face of contingency. Where Deleuzian combat draws attention towards a dynamic interaction between antagonistic forces, Culbert considers Machiavelli's advice to the Prince, when he compares fortune to a raging river that should neither be submitted to, nor stood up against (Machiavelli 1992, p. 67, cited in Culbert 2008, p. 150, 161). Rather, when the weather is fine and the water is low, one should prepare. Certain techniques employed by self-help group members are borne out of understanding variations in experience over time in relation to their distress, in order to take advantage of them. For example, aided by the use of mood-charting, one member of Bipolar UK recognised that his mood dropped every Saturday (after the intensity of the working week), and consequently planned our interview for the Saturday morning to 'take the edge' off the dip (Interview with self-help group member 2011). Another example is how voice hearers recognise that voices need to be engaged with as soon as possible, in order that the voices do not get more and more persistent. This has produced tactics such as voice-hearers pretending to be on the phone when in public, in order to be able to talk aloud without feeling judged by onlookers, and ways of negotiating time-slots with voices for when one is able to speak to them, so that one can ensure they are ready and able to do so (Smith 2001).

What I am suggesting is that the process of self-experimentation, through deferring and/or frustrating judgement, occurs both within individuals and within groups, and that as crucibles for learning, group members come to possess resultant capacities and techniques that can be deployed in other contexts. The authority relationship being expounded here is self-grounded, in the sense that an objective knowledge emerges out of experimentations amongst the 'parts' of oneself, as shared, discovered and analysed through self-help practices that defer or frustrate the making of judgements (see also Blencowe 2013; Brigstocke 2013). How is this authority relationship maintained and passed on? In the next section, I turn to consider the motor of transmission of experiential authority production within self-help and support practices in mental health.

Tradition and the weightiness of knowledge: memory and boundaries

In Arendt's ([1954]1993) formulation, testimonies passed down through the generations reproduce and augment the authoritative relation. She bases this model of authority on Roman political authority, wherein a central place was accorded to the myths of the founding of the *civitas*, myths that were passed down from generation to generation, both augmenting and perpetuating the authority of the Senate in its capacity to advise. For Arendt, in modernity we can no longer rely on tradition,

and for this reason she suggests we should ask not what authority *is* but what it *was* (Ibid.). I suggest that this model of authority does shed light on the mental health expert-by-experience, but only after critically engaging with tradition by way of other terms. Indeed, in relation to the case studies considered here, it could be argued that the HVN has its own 'foundational story', in the moment that the Dutch psychiatrist Marius Romme realised that he had no grounds for rejecting the theories his patient Patsy Hague had about her voices.[10] However, by contrast, Bipolar UK does not appear to offer, and certainly does not rehearse, a story of origin within group meetings or in organisational reading materials, and one was not offered through interviews conducted with key members of organisation at local and national levels.

Nevertheless, records of collective struggles lie at the heart of social movements. In relation to the service user and survivor movement, Coleman (2008) suggests,

> As in all social movements, the crucial move is not simply to speak to power, but to cultivate a historical consciousness of this process, for it is by this cultivated memory that a politics is propelled from the present into the future, to respond to changing conditions. (Ibid., p. 357)

When analysed through the lens of collective memory, mental health expertise-by-experience bears functional similarities with models of traditional authority. For Arendt, the significance of tradition for authority lies, in part, in testifying to an origin which grounds that authority in an outside inaccessible to authority's subjects. I have suggested that experts-by-experience's claims to truth are produced through practices of self-help while not actually being foundational to those practices. Knowledge is produced in the form of techniques and capacities for working on experience through self-experimentation, where the limits and boundaries of experience itself are what are being worked upon, recursively. However, if techniques for working upon experience drive the authoritative relation, this points to a far less retrolinear conception of the 'depth' of tradition: one that is not towards a point of origin in the past, but diffused across the techniques and capacities practised by those with expertise of working on distress.[11]

Indeed, many diverse stories of what has happened to individuals, and what self-helpers have heard has happened to others, combined with descriptions of techniques for working on the self that have succeeded or failed, are used by different self-helpers to testify to the efficacy of self-help. This suggests locating the weight of authority in the practising of techniques, including that of storytelling, of the groups themselves. 'Expertise-by-experience' then is not predicated upon belonging to a particular group or being the actor at the centre of a story of origin, but upon living with and working through mental distress. Self-help practices provide spaces for the self-work that transforms a newcomer into an experienced veteran, who not only has (co-)produced and experimented with various techniques for working on the self, but understands through the sharing of stories the vicissitudes in their and others' uses of these techniques (cf. Borkman 1999, p. 162, opp. cit). It is the depth, complexity and richness of connections that matter, regardless of whether or how these are distributed. Sharing similar experiences gives them a 'weightiness',[12] and this weightiness is a necessarily networked phenomenon.[13]

To summarise, the experience of veterans in self-help groups does not become authoritative because they suddenly understand the 'truth' behind their experiences

– a truth beyond what newcomers to groups know. Rather, experiences become more 'weighty' as they collectivise over time, that is, as self-helpers identify similarities and differences in stories they share with one another, about their respective engagement with their distress and the effects of their distress. The centrality of storytelling within self-help and support practices enmeshes individual trajectories with understandings of similar ones, criss-crossing individual's narratives with those of others and using (parts of) others' to rework the individual's own. 'Learning' then becomes a movement through stages or generations of investing in particular experimental parameters, where the (individual or collective) self is the dependent variable in question. This offers insights into the deep connections between authority, memory and ageing. In self-help groups, it explains the difference between the newcomer and the veteran. Consequently we can understand why, for example, Borkman explains in relation to three progressively developed stages of self-helper 'maturity',

> [o]ne of the biggest mistakes that observers, self-help bashers, and novices make is assuming that a participant in stage 1 with a victim mentality is a representative of the group and can faithfully represent its ideas, beliefs, and practices to them. (Borkman 1999, p. 157)

What we find being developed is a form of authority that rests on experience, without relying upon tradition as anchored in singular origin stories. In this sense, what is crucial about tradition is its ability to produce a style of reasoning (Hacking 1982), a resource for a particular mode of ongoing, indeed inexhaustible, inquiry. Through self-help's experimental inquiry, sharing with one another and investigating using one's body in ways that make experience more weighty, experts-by-experience earn a degree of influence through their ability to speak on behalf of a broader range of encounters with mental distress.[14]

Granting authority: openings for participation

If capacities for deferring and disrupting judgement in relation to knowledge production are practised within self-help spaces for the purposes of working through mental distress, do these capacities transfer through to the experiential authority relation itself? An interview with the local (and long-term) activist provides evidence to suggest that such links are worth further investigation. She describes how self-help practices can help to develop an enhanced capacity to listen, an awareness of interpersonal dynamics and an ability to gauge subtext in conversation:

> … I'd actually had to watch what was going on [amongst service staff] in order to survive. So I think there is something about being in that vulnerable position in the services that makes you very, very conscious and very aware of what's going on with other people … And more able to hear what people are saying. Yes I think we do listen better, on the whole … I suppose that when you're in a management meeting let's say, it might make you better able to be more critical about what's going on, what's being said. … I think we're much better. We are! I think we're quite good at seeing what the subtext is. Am I speaking just for myself here? No I don't think so, I think … if nothing else, in a self-help group you learn to criticise treatments, and to see psychiatrists as fallible people, and mental health workers as fallible people. (Interview with local activist 2011)

On engaging with fear and risk, she continues:

> I suppose we're less frightened of things, aren't we? We're less frightened of … do you know I've never really thought about it? I think we're less frightened of people who break the rules in meetings. … Because you know, we actually know about risk. So I think we have a lot more understanding of those sorts of issues, and are much less frightened of those sorts of issues than ordinary staff are. (Ibid.)

This last quotation captures a moment when the local activist realised that she had never really considered how she and other service users and survivors who had developed an expertise in relation to their distress possessed correlated communicational capacities that others without experience of distress might not – an empirical question that lures a whole field of inquiry.

These quotations illustrate some positive capacities that are associated with the authority of the expert-by-experience. However, how might the subjects of their experiential authority be understood to *grant* experts-by-experience such an authority? A crucial function of the techniques produced in self-help groups is to communicate the experience of mental distress to those who have never experienced, for example, the mood swings of bipolar, or unusual sensory stimulation such as the hearing of voices. For instance, a 'voices simulation exercise' is a role play developed within the HVN self-help groups that mimics the experience of hearing voices, and demonstrates that the reactions of voice-hearers to their voices and non-voice-hearers to the role play are largely consonant.[15] Such techniques have the effect of challenging the distinction between the 'sane' and the 'mentally ill' person by making the experience of distress accessible to others. Put another way, it makes the distinction between the 'mentally ill person' and the 'person experiencing distress' audible. I suggest that experiential authority of the kind I have been arguing for would become increasingly relevant to those outside of the groups the more this distinction between 'normal' and 'pathological' is broken down through such communication strategies. This is because the more acknowledgement there is that mental distress can be understood by all, the more the advice of those who have 'been there' becomes pertinent to all of us. Hence techniques for making distress understandable and communicable allow subjects to be able to grant authority to experts-by-experience in the first place. The conceptualisation of the authority of the veteran over the newcomer is analogous with the conceptualisation of the authority of the group over those with no experience of distress. These are experiments upon problems that one can imagine occurring to them, or people they know, in the future, because, in part, of the techniques produced within self-help groups that render such empathy imagin*able* to others. It ties the authorising of the expert-by-experience to the breaking down of the barrier between 'mad' and 'sane', revealing the political gains made by the idea of an expertise-by-experience in mental health, in claiming an authority over everybody, rather than simply over the newcomer to the problem. Moreover, through the communicational techniques alluded to above, non-self-helpers may increasingly come to realise that they are 'a bit bipolar', or have symptoms of anxiety, and so on, and that they have perhaps also become effective (and to a degree 'expert') in dealing with these distressing experiences.

There is no guarantee that the 'fact' that mental distress can affect anybody will necessarily improve the *relative* authority of the expert-by-experience, for example

in relation to the medical model of illness, or the concerns with risk that animate strategies of risk management. Pilgrim (2005, p. 24) warns that the 'it could be me, it could be you' Russian-roulette acceptance of mental illness is bound up with the politics of making psychiatry into a medical speciality. He explains that advocates of a medical model view claim that mental illnesses can only be destigmatised by treating it like any other medical problem, i.e. as something to be 'cured'. Yet such a stance exists in tension with the meaning-making that constitutes the authority of the expert-by-experience, who in the process develops capacities and techniques for exploring and communicating their experiences. The stigma of mental illness all too often grows out of the silence that accompanies a lack of meaning, as the local activist illustrates:

> I have sat with psychiatrists who've told me about how they – about their diabetes, or their bad leg or whatever, and the issues there are around that. And how they will identify with this and that [mental health] problem. They will quite happily do that. But they won't sit there and say, actually I get depressed. Um, or actually I tried to kill myself once. They won't do it, they can't do it. (Interview with local activist 2011)

The use of techniques of communication to heighten an awareness of the continuum of experience of mental distress merely raises the stakes in this power play between different kinds of rationalities for dealing with distress – whether self-help, bio-medical, governmental or other. Making distress in this sense understand*able* is a precursor to the rationalities[16] that engage with it further. However, it is just as easily incorporated into a medical model approach, which has then a greater claim to widen the appropriateness of medical interventions.[17] It does appear to destabilise the governmental concern with risk, imbuing 'risky' behaviour with a rationality that can then be worked upon, rendering risk understandable rather than simply calculable. Nevertheless, the identification of a coherent style of reasoning that is particular to communities of self-helpers draws our attention on the one hand to techniques of communication that bridge the gap between 'normal' and 'pathological', and on the other to capacities manifest in self-helpers that are mobile and whose uses extend beyond personal engagement with distress.

Conclusion

In this article I have traced how the radical survivor movement has transformed, in large part, into the service user movement (Rissmiller and Rissmiller 2006), and thereby become subject to governmentalising logics that seek to limit its scope and capacities. This governmentalisation of service user spaces can be disrupted and contested through collective yet self-directed projects borne of self-help and support practices which seek to engage with and better understand the experiences of mental distress.

I suggested that one driving force behind the experiential authority of 'experts-by-experience' can be found in processes engendered within the experimental crucibles of grass roots self-help and support practices, where individuals who experience mental distress experiment with ways of working on their experiences, developing ways of navigating through periods of distress. In the process, members develop certain capacities and techniques that I claim are central to expertise-by-experience. There are certainly other elements to such an expertise,

such as shared experiences of mental health service use, but in this article I have tried to focus on the emergence of capacities and techniques in self-help and support groups that accord with an expertise in relation to distress while simulaneously possessing wider political potential. The service user and survivor movement should be recognised as contributing to 'user involvement' through developing many and varied techniques for working on and sharing experiences of distress. Experts-by-experience return, as Laing (1967, p. 107) lyrically notes, like explorers with knowledges beyond our mere speculations. Their force is not captured through either Beresford's consumerist or democratic frameworks for understanding involvement. By bearing witness to how the authority of 'experts-by-experience' is of a different kind than that of the service user representative, and by offering theoretical resources for reconceptualising it, new potentials for contestation and activism are brought into view.

At the same time, the theoretical implications of this kind of 'experiential authority' are interesting, insofar as they force a reconsideration of the meaning of 'traditional authority'. Far from juxtaposing traditional authority on the one hand with the types of authority possible under modernity on the other, self-help and support practices offer contemporary examples of a form of authority and expertise that relies on collective meaning-making, the sharing and connecting of experiences, and the production of a body of collective knowledge around ways of working on experience at its boundaries. The resultant knowledge, which I conceptualise in terms of capacities and techniques, is able to contest the knowledge and authority of both medical psychiatry and governmentalising logics, in new and potentially radical ways. However, what are the implications for how we think about the relationship between tradition and community today, and indeed, does this offer insights for projects that seek to trouble the understanding of 'modernity' as a particular epoch?[18] And what are the stakes in raising a 'counter-modern' narrative that connects the self-help practices considered here to the kinds of authority practised, for example, by village elders in other times and places? I suggest that these are pressing questions if we seek to draw out the political potential of what is specific to the knowledge and experiences of the mental health service user and survivor movement in non-tokenistic ways.

Notes

1. At http://www.bipolaruk.org.uk [Last accessed 13 May 2012].
2. At http://www.hearing-voices.org [Last accessed 13 May 2012].
3. There is another important thread to the history of recent government policy, concerning the development of mechanisms for coercing mental health service users in the name of 'public risk'. Notably, service user representatives working with the Department of Health in 1998 infamously resigned upon realising that the introduction of compulsory treatment orders was non-negotiable (Tait and Lester 2005). By 2002, the Mental Health Bill (DoH 2002) clearly framed mental healthcare issues in terms of risk to the public instead of service user rights.
4. See, for example, 'The Doctor Who Hears Voices' documentary, available at http://www.channel4.com/programmes/the-doctor-who-hears-voices [Last accessed 15 October 2011].
5. This is a finding from seven interviews with national and local members of two self-help and peer support group networks, the Hearing Voices Network and Bipolar UK.
6. See Archibald (2007) for a four-way typology.
7. For the remainder of this paper I emphasise expertise-by-experience that emerges in relation to working on experiences of mental distress. Other kinds of expertise-by-experience exist in mental health, such as the subtle expertise of dealing with psychiatrists, of

engaging efficaciously in service user involvement mechanisms and so forth. I suggest that all these different, repeated and shared experiences provide crucibles for developing an expertise-by-experience, and would benefit from being understood in the same way that I am developing here in relation to the engagement with mental distress.

8. This is evident from their websites, and concurs with interviewees from both organisations.

9. Such a process is reminiscent of Simmel's vitalism. See Simmel (1971).

10. For more details, see http://www.psychminded.co.uk/critical/marius.htm [Last accessed 10 July 2011].

11. Cf. Brigstocke *et al*. (forthcoming), where the authors develop a sustained critique of the framing of experience-based authority as necessarily traditionalist, in the sense of orientated upon the past.

12. Honig (1991) asks her readers where the weight of authority can come from, if not from a transcendent ground?

13. 'Community' in this sense is immanent to collective, shared practices of self-experimentation. This way of conceptualising community incorporates disagreement and discord between selves in a different way than Kirwan's (2013) claim that 'community' exists in its absence or retreat. Nevertheless there may be a fruitful conversation to be had between these positions.

14. I leave a question hanging: given that self-help groups are often defined in an ideal-type sense as non-hierarchical spaces of mutual trust (e.g. Lindow 1994, Borkman 1999), how do we understand the empirical fact that certain members of the groups have greater influence over others, and that this influence is not a kind of persuasion between equals but an authority grounded in different experiences, and itself grounding a difference in power?

15. See http://www.intervoiceonline.org/2007/6/28/an-exercise-in-how-to-replicate-the-experience-of-hearing-voices [Last accessed 15 October 2011].

16. *qua* styles of thought (Hacking 1982).

17. Moreover, we should be wary of dichotomising self-help and medical approaches – Bipolar UK for example is largely accepting of a medical model approach to 'bipolar disorder' (the clue is in the name …).

18. For example, see Foucault (1984) on the task of construing modernity as an *ethos* rather than an epoch. We might then ask, what is the *ethos* proper to the experiential authority of the expert-by-experience?

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