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Service user / survivor led research in mental health: epistemological possibilities

Introduction

This paper is concerned with exploring possible epistemological bases for service user / survivor led research in mental health. By ‘research’ I include both empirical and conceptual work which always entail one another even if this is not explicit. The purpose is to delineate different discourses which offer possibilities for grounding such research epistemologically and to compare them in terms of both argument and praxis. It is not suggested that epistemological arguments exhaust what is contained in the diversities of user and survivor led research and theory currently in existence but that this is one level where differences may be clarified, comparisons made and claims adjudicated. The discourses examined are the Patient and Public Involvement (PPI) tradition that has emerged primarily in England over the last twenty years, the Canadian body of work encapsulated in the term Mad Studies and its recent flowering and reception in Europe, critical theory more generally and finally the more specific critical theory stance of Standpoint Epistemology especially as articulated in the work of Sandra Harding and Donna Haraway. As well as critically interrogating these approaches, I aim to bring service user / survivor led research and its conceptualisations into dialogue with more established critical theory. The aim of the paper is modest in that its intervention is at the level of knowledge and its concurrent praxis. As said, this hardly exhausts survivor work but the current distribution of knowledge privileges certain spaces – primarily the academy – and so there is a case for intervention both within dominant epistemic spaces and from outside them.

The English Tradition of Patient and Public Involvement (PPI) in Research

The focus here is on England rather than the devolved nations most simply because the flourishing of PPI in research was until recently very well-funded in this country and there was considerable infrastructure. This was not the case in the devolved nations. As a result, England and this tradition is important for service user / survivor involvement in mental health research first because of the sheer volume of work that has been produced. For example, Patterson and colleagues conducted a survey to find out the numbers of people in England who identified as ‘service user researchers’ and described what they called a ‘hidden workforce’ of 800 persons. This compares to numbers of less than 10 or 20 in most countries (Patterson, Trite et al. 2014). Again, it is to England that many service user / survivor (‘consumer’ in Australia and New Zealand) researchers turn when they wish to develop their work. The current author, as lead of a service user research unit in London, receives dozens of such approaches per year. For this tradition then, England is influential.

Historically, this tradition grew out of a decision by the Department of Health in the UK in 1996 to fund a unit named ‘Consumers in NHS Research’ (later INVOLVE www.invo.org.uk). This unit was across medical specialities and formed in the belief that involving ‘consumers’ would make research in the NHS more relevant. Later the remit was widened to include social care and public health. Two things are notable about the early days of INVOLVE. First, mental health was always heavily represented and second the remit was broader than it subsequently became as it included what was termed ‘user-controlled research’. I return to both of these issues below. The next important

moment occurred when the National Institute for Mental Health was formed in 2006 and topic-specific networks were established. One of the first of these was the Mental Health Research Network (MHRN) and it put a premium on 'user involvement in research'. By this time Departments of Health had been devolved and so the NIHR was England-specific. It can be said that the MHRN firmed up what became the English tradition of PPI in research. The Patterson et al survey was largely a survey of those involved in the MHRN. This body ceased to exist in 2014 and, it might be argued, PPI in research in mental health became diluted. This posed both threats and opportunities for service user /survivor research in mental health.

It is important to point out that these centrally funded and governed bodies never exhausted survivor led research in England. The early commitment to user-controlled research happened at the behest of survivor researchers and has been continued by them. This includes people working freelance and organisations such as Shaping our Lives (www.shapingourlives.org.uk). This is much less constrained in the forms of research it can do whilst and at the same time it is not nearly so well resourced. Equally, the strength of mental health research and its focus on service user involvement in NIHR was partly because of a very different tradition of research in England, empirical and conceptual, pioneered by members of the survivor movement in the mid-1990s (Beresford and Wallcraft 1997, Faulkner and Layzell 2000, Rose 2001). Today, freelance researchers and those attached to user groups sustain a grounding in the user movement difficult for some in universities to sustain and they critique the exclusivity of mainstream work as well as its restricted understandings of issues such as peer support (Faulkner and Kalathil 2012). The situation in England then is not simple but nonetheless, I will focus on the PPI tradition here because of its epistemological specificity and because of its influence.

Research done under the auspices of the MHRN largely took place in universities with some involvement of the voluntary sector. The mantra went that this made research more 'relevant' to service user concerns thus leading to greater 'patient benefit'. However, mainstream research methods were rarely disturbed. My unit's own website (<http://www.kcl.ac.uk/ioppn/depts/hspr/research/ciemh/sure/index.aspx>) boasts of involving service users in all stages of research from design through data collection, interpretation of results and dissemination. And this, although limited, is an achievement considering the research staff all have experience of using mental health services, a kind of 'double identity' that does make a difference as we shall see (Rose 2014). But the point for now is that mainstream research methods – randomised controlled trials and cohort studies – supervened although increasingly service users introduced qualitative research and adapted some mainstream methods as well. But to the extent that mainstream methods are embraced, these may not be the best way of representing the concerns of service users / survivors which is the ultimate aim.

A study will not meet the requirements of the MHRN portfolio unless it is of 'sound and ethical design'. This begs a multitude of questions but they are mostly answered internally with reference to mainstream scientific norms and practices. It is worth pointing out that more of the studies done under these rubrics were tests of new psychological, or more rarely, social interventions so we are not here dealing with a straightforward 'medical model' in the sense of a body of work dominated by pharmacological studies. However, we are dealing with a *clinical* agenda and a very individualistic one at that (Jones and Brown 2012). This is not surprising given that these studies are being conducted in departments of psychology and psychiatry but it is worth spelling out to demonstrate

that this agenda closes off a multitude of possibilities. Even where the 'intervention' is less conventional this occurs. A current very large study of 'peer support' has adopted the method of the randomised controlled trial and the primary 'outcome measure' is readmission to hospital (Gillard, pers. com., 2015). This study has robust 'Lived Experience Advisory Panels': their influence is yet to be seen.

It is notable also that whilst this tradition was being established, and concurrent with earlier more user-led approaches, parallel work was being conducted in the USA (Clay 2005). But the two strands of work largely proceeded unaware of each other. At least this was the case until Jean Campbell, the leading US survivor researcher, visited Utrecht where other European service user researchers were present and so their work was mentioned in her 2009 chapter (Campbell 2009). Campbell's position is that if service user research is to be credible and legitimate then it must make use of mainstream methods, including complex quantitative techniques. This is in contrast to even the English tradition and represents an endorsement of mainstream methodology.

In the last few years there has been pressure to show that this involvement – in all medical specialities, social care and public health – has had 'impact'. This has been very difficult to demonstrate. The reasons seem obvious. It is because nothing much has changed at the level of research itself. In particular, the methods remain the same and so involved service users are very constrained in what they can achieve. Other things have changed, most notably a democratisation of science in respect of who gets access to the academy (Rose, in press). But as to changing the means of knowledge production, this has signally failed for the most part.

The reasons for this are not just the pursuit of a hidebound set of methods. Methodology is itself the epistemological underpinning of the kinds of 'science' pursued in departments of psychiatry and psychology as well as the rest of medicine. Committed to ontological and epistemological realism, the belief is that if the right method is pursued truth will be revealed. This is what makes the claim epistemological and in this respect it is a singular and universalising claim. Now, what is clear is that this method is not delivering in psychiatry today. Effect sizes are small if they are found at all and heterogeneity huge. NIMH has declared that diagnostic categories enshrined in DSM5 cannot be the basis for research. I have witnessed researchers faced with insignificant findings and their response is to do more of the same on populations further and further removed from the original topic of interest. They occupy what Kuhn calls 'normal science' yet there might soon be a paradigm shift brought about by collapse under internal strain and external objection (Kuhn 2012). It is possible service user knowledge is hastening this. This is not to say all clinical researchers are doing mischief, just that the science is deeply problematic. Moreover, many practitioners actually take little notice hence the current rush to 'implementation science' as the latest version of 'evidence based medicine'. The fact that practitioners are recalcitrant in their adoption of the 'evidence' itself undercuts the idea of a psychiatric monolith at an institutional level, a point to which I shall return.

Staying with the UK, there have always been other traditions of survivor research and I have referred to them already. Particularly, there are survivor-controlled organisations that conduct research and independent consultants who often link with user organisations. Such researchers have retained direct links with the user movement, although it has changed greatly over the years, and also are not constrained by mainstream methodologies and attendant epistemologies. They are able to make very different critiques of mainstream services (Faulkner 2005) and foreground issues like peer-

support in a user-centred way (Faulkner and Kalathil 2012). Leading BME service user researchers can link to their own organisations and theorise this as well as work with others (Kalathil 2008, Kalathil 2010). This work is not well-resourced, a major issue that is unlikely to be resolved whilst major funders cling to certain methods. I return to this later.

Recently, there have been attempts to produce a different knowledge base for this kind of research, either specifically sociological (Staddon 2015) or beginning to draw on work I will refer to later (Sweeney, Beresford et al. 2009). However, what may hasten the collapse of the English PPI tradition is also more prosaic. The infrastructure that has made that country such a fertile field for this research has now vanished and the sector is regrouping (Rose 2015). Part of this has been the attraction for some of the proposal of a new academic discipline with a very different, and much more explicit, epistemology. This project is named 'Mad Studies'.

Mad Studies

Mad Studies is primarily associated with Ryerson University in Canada and grew out of work in disability studies but it has attracted considerable European interest quite recently. It must also be noted that such an orientation has existed in Scotland for some time now. The field is currently burgeoning. In the last three years two collections (Menzies, LeFrançois et al. 2013, Burstow, LeFrançois et al. 2014) and one monograph (Burstow 2015) have appeared from Ontario alone. Unlike the English work described in the last section, this project is less empirical than a sustained onslaught on the very epistemological basis of psychiatry and its attendant practices as well as a developing and diverse alternative. There is a parallel movement in Europe which has a long history in the argument for user-controlled research but which has recently been revived (Russo and Beresford 2015). Key here has been the user-controlled organisation Shaping Our Lives it's Chair has a chapter on the role of service users in academia in the Burstow et al collection (Beresford and Menzies 2014). The remit of this organisation is social care recipients generally and so there is a parallel history in disability studies in the English reception of this work. In 2016, the first book-length treatment of the field from Europe was published (Russo and Sweeney 2016).

Mad Studies is a new and developing field and for that reason difficult to summarise. Further, this paper is concerned with epistemology and so is more specific in its focus. Mad Studies exceeds epistemological questions and cannot be reduced to them and my treatment is therefore particular. However, the general framing of Mad Studies is a critique of the 'medical model' and so it turns on its head the model which underpins the PPI in research tradition dealt with in the last section. Critiques of the 'medical model' are not new but this discourse systematically exposes the values and presuppositions which lie behind psychiatric thinking and practice and at the same time offers alternatives both conceptual and practical. Important is the observation that whilst the truth claims of mainstream mental health thinking rest on the privileging of *method*, behind this is a set of ontological assumptions about what madness is, how it comes about and how it should therefore be treated.

The fullest epistemological treatment of this approach comes in Burstow's *Psychiatry and the Business of Madness: an Epistemological and Ethical Accounting* (Burstow 2015). Written by a radical feminist psychotherapist, it also has plenty to say about practice. Burstow is an important figure as she is also a co-editor on one of the other Canadian collections (Burstow, LeFrançois et al. 2014) and has a paper in *Mad Matters*. A review of the 2015 text has appeared elsewhere (Rose, 2016). Suffice

to say here that the structure of the argument is to reverse the values of psychiatric writing but to *retain* the form of the argument. This is clearest in her treatment of history but applies also to the dissection of diagnostic categories and the place of Big Pharma. In addition, in respect of the latter, the argument is basically derivative upon Breggin and Healy (Healy 1997, Breggin 2007). She neglects to mention that David Healy sees a place for ECT in psychiatry. She further cannot settle accounts with Michel Foucault either historically (Still and Velody 1992) or in terms of the role of psychiatrists as such (Foucault 1967).

Burstow is not representative of the field of Mad Studies by any means but she has offered an epistemological accounting. My last two points above – regarding Healy and Foucault - bear on the question of whether psychiatry is an homogenous and homogeneously wrongheaded field. Does it have a singular and irreducible logic? For Burstow this is so without question. The more general issue is whether it is a fundamental proposition of Mad Studies as a field? Of course this question assumes there is such a fundamental assumption and some writing in this approach are less concerned with psychiatry at all and more concerned with alternative conceptualisations, methods and practices. In Canada this was the case very early on (Church and Reville 1988), it characterises some of the chapters in *Mad Matters* (Menziés, LeFrançois et al. 2013) and there is equivalent if more nuanced concern expressed, for example, about who owns our ‘stories’ (Costa, Voronka et al. 2012). Lucy Costa has been a pioneer of this approach.

For some writing from this perspective, Mad Studies emphatically does not have this singular logic. As Beresford proposes in his forward to the book *Mad Matters*, this is a ‘for’ rather than an ‘against’ body of writing and praxis (Menziés, LeFrançois et al. 2013). Second, it has had profound impact on the second tradition in England (Scotland has had its own version for some time) that I described and has reach in Europe and the United States. Finally, it has the potential to create vibrant new ideas and if it is a developing and flowering affirmation of mad discourses then we do not have to worry about singular epistemologies. We do not have to worry about epistemology at all in one sense – it is part of the end of it that has been coming for some time.

The question I have to put is this: is Beresford right, that this is a ‘for’ rather than an ‘against’ approach that is developing? I am not convinced, at least not yet. On my reading, psychiatry remains the foil against which Mad Studies is articulated. The conceptualisation of psychiatry remains, for the most part, monolithic and singular. The subtitle of the new collection by Russo and Sweeney is “Challenging psychiatry, fostering Mad Studies”. It could not be clearer albeit this is a strapline for a complex book. Even more specific pieces that I find very helpful have psychiatry as villain lurking in the background (Costa, Voronka et al. 2012). As I say there is nothing to disagree with here, quite the reverse, but it is located in a bigger picture and it is the bigger picture that concerns me. For as long as the foil is conceived as epistemologically and institutionally singular, this puts limits on what can be articulated as alternatives. Epistemological arguments do not exhaust these possibilities and do not prevent ideas that exceed them. But they are constraining even whilst, perhaps especially whilst, they remain invisible.

Mad Studies and the Mental Health Mainstream

What are the consequences of this for analyses of the ‘mental health’ field as such? To the extent that Mad Studies exemplifies it, epistemological singularity is problematic especially when it is a matter of social discourses, institutions and practices however constrained and constraining these

might be. It has long been recognised that history is never linear (Butterfield 1965) and that institutions are permeable (Miller and Rose 2008). One response to this is to say that discourses and institutions have a logic but that *individual practitioners* manage to escape this and behave decently. This has some merit but I would argue that such individuals are located within aspects of the more general space that does not align with the overall 'logic' and this rather undermines the very idea of such a generality. Practitioners resist the 'evidence base', as pointed out above, and Jones has shown that frontline staff even dismiss 'boss texts' such as DSM (Jones 2015). As regards research, biomedical psychiatry in the industrialised West is currently in the ascendant and other approaches such as social psychiatry and psychoanalysis seem to have dimmed. Nevertheless, they have a legacy and that legacy is part of the current make-up of the field. Furthermore, psychiatry is now in some disarray: DSM categories are no longer acceptable in research, Pharma has pulled out of CNS drugs except for the dementias and when it comes to 'evidence' effect sizes are small and heterogeneity huge. The methodology is failing, the universalism is cracking, as pointed out above. Two recent pieces by the English psychiatrist Robin Murray have drawn huge and mixed reaction from both mental health professionals and service users. The first argues that maintenance anti-psychotic treatment may do harm rather than good (Murray, et al, 2016) and the second is a self-reflection on his own commitment to biological psychiatry which in retrospect he believes was wrong (Murray, 2016). Whatever the merits or demerits of these articles they are symptomatic of the cracking to which I refer. They have even featured positively in the online site *Mad in America* which devotes itself to critiquing biomedical psychiatry. Of course the field will try to reinvent itself but to assume a singular logic diverts attention from the very real fracturing that is occurring internally, the growing dismay of many and the opportunities this affords other discourses. I therefore argue that to the extent that Mad Studies assumes psychiatry is an homogenous field and a malevolent field at that, it ignores both a complexity and a fracturing that could see psychiatry falter quite radically and actually open spaces, internal or external, for Mad people's knowledge to be pursued. I do not argue that psychiatry is a loose assemblage of concepts and practices where anything is possible. Far from it. Rather that its lack of a singular underpinning and its internal contradictions are opening new possibilities. Still less is this a counsel of 'reform' which depicts better the PPI approach described above where, often unknowingly, arguments work to cement mainstream knowledge rather than take hold of its weak points and challenge and replace them with new understandings and new practices. Clearly, it does not obviate the possibility of co-option. There is also a very specific issue that mitigates against this which Miranda Fricker has captured in the terms 'epistemic injustice' and 'epistemic violence' (Fricker 2007) and which is widespread in the mental health arena. That is to disqualify us as knowers just because we are positioned as irrational, unreasonable, incoherent, lacking insight and so on. Bluntly put, the mad cannot do 'science' because that space of ultimate rationality is by definition closed to irrational beings. From this perspective to take on psychiatry may look an impossible task; my advocating it rests on its internal contradictions and the power of the collective that is external to it.

The main point is that Mad Studies as a positive flowering of new knowledge could also take account of the internal fracturing of the discourse it articulates itself against. Further, if we do not do this we risk leaving behind the millions of people to whom choice on this matter is closed. That is, those damaged and oppressed by mainstream psychiatry will not be liberated, in my view, only by discourses and practices which are too easy to dismiss if they do not work at least in parallel with internal critique. To this I now turn.

Survivor research and critical theory

Survivor movements often take the form of identity politics just as did early feminism, disability movements, anti-racist movements and movements such as Gay Pride. Silenced and despised groups re-valued their experience and engaged in a cultural politics of affirmation. The response to oppression and discrimination were often framed around new identities – collective and individual. These movements were not separate, they emerged together in different countries for different reasons but often through a discontent with a Marxist exclusive focus on class. Much theory emanating from these movements both documented and conceptualised the nature of and obstacles to these struggles at both collective and individual levels (Bhabha 1984, Watney 1997, Friedan 2010). At the same time, some writers eschewed purely cultural studies and allied these with forms of post-Marxism (Hall and Du Gay 1996, Fraser and Honneth 2003). Nancy Fraser's work has been taken up in some survivor theoretical writing and I shall return to this. I would like to consider survivor identity politics, as one response to marginalisation, and its theorisation in terms of this body of literature.

First, I need to say that to do this is walking on egg shells. Identity politics has always privileged the experience of marginalised groups and this is true today in survivor talk and writing: lived experience; experts by experience; auto-ethnography. I have no wish to get rid of words or police them out and it is significant that a group whose very speech has been deemed meaningless should foreground the importance of their experience (cf. Spivak 1988). The fragility of identity politics in this domain means discussion must be circumspect. However, in critical theory there is a long tradition of critique of 'experience' as a foundational category and I think we need to pay it some attention.

An important work here is Joan Scott's 'Experience' originally published in 1991 (Scott 1991), although critical Black scholarship examined subjugated subjectivities long before (Fanon 1967). Scott's work was important but not by any means universally acclaimed. Many feminists in particular took it to be an attack on the 'authenticity' of their experience. So we must be careful; appeals to experience on the part of service users are fragile. However, Scott's argument is that radical history in particular but also other critical discourses rely on experience as a foundational category that naturalises excluded groups and identities whereas these should be historicised. This means recognising that 'experience', rather than being fundamental and 'authentic', is shaped by language, the concepts it embodies and the social institutions which structure it. Importantly, discourse entails power and it is *shared*. I will return to this but first need to address a difficulty.

Long before Scott published her article, women of colour critiqued the Whiteness of the feminist movement, most notably beginning with bell hooks (Hooks 1982). The argument was that the Patriarchy analysed by feminism had no place for the experience of Black women – it was a White Patriarchy. This developed into the concept of intersectionality (Crenshaw 1991) later itself interrogated as to its complexity as marginalisations can be multiple (McCall 2005). The relevance to Scott is that much as she critiques experience as a foundational category her post-structuralist alternative of a positioning in discourse itself verges on the universal. It is perhaps not coincidental that this argument has entered Mad scholarship through the voices of Black survivors, notably but not only feminists (Kalathil, Bhakta et al. 2011, King 2016). King in particular speaks from the

position of an African Caribbean man in relation to white psychiatry. That position has been documented for many years (Fernando and Keating 2008) but King's analysis is profound. The importance of the theorisation of intersectional difference does not entirely vitiate Scott but it does foreground structures of discourse and power rendered invisible in her argument.

However, another turn that has taken place in survivor writings, especially those influenced by phenomenology, is to emphasise not structural difference but multiple and to a degree individual ones. This is clearest in Jones and Kelly (2015). The critique of experience here is different and the main point seems to be that using experience as a foundational category, even strategically, effaces the deep and multiple heterogeneities, renders them invisible and unspeakable. Wherein do these heterogeneities lie? They lie in response to distress; in length and nature of distress; in responses to and of the mental health system; in ideological and epistemological differences; in respect of class, gender, ethnicity, disability, sexuality; even differences in 'diagnosis' and so forth. On occasion the conclusion seems to me to be that we are all different *as individuals* and so individual experience in fact reappears ascendant.

Do the user / survivor movement and its academics have any pointers towards to tackling this issue? I would argue that there are parallels with activism and user/survivor groups. Part of what these groups do is share, validate, collectivise and thereby reframe and render more general the experiences that individuals bring to them. So without ignoring difference, my argument is that the focus must be on collectives and that goes for those of us who are trying to thrash things out intellectually as well.

The second issue for me is the engagement with critical discourses which have picked up and developed Scott's critique of experience. These include some texts in feminism, later post-colonial studies, queer studies and disability studies. It is important to articulate our field with this theorising but I do not think we should underestimate how difficult it is. Each of these bodies of work are deeply engaged with the others. However, they hardly ever refer to madness. Madness is an invisible category. In his 1967 preface to the English edition of his *History of Madness*, Foucault wrote about how the mad had been silenced by the Enlightenment, silenced by a monologue of reason about madness (Foucault 1967). I do not argue that we are the last subjugated group but it is not easy to begin a dialogue with other critical discourses and, conversely, not everyone who lives under the description of a diagnostic label wishes to identify as disabled or, indeed, Mad (Bereford, Nettle et al. 2010, Spandler, Anderson et al. 2015).

So if 'experience' is a difficult category and identity politics only a partial response to oppression is there anything to learn from later critical theory? And what are the epistemological implications? I propose here to draw on the feminist writings of Nancy Fraser and Wendy Brown. In the UK collection edited by Patsy Staddon (Staddon 2015), Lydia Lewis draws on Nancy Fraser's concept of 'misrecognition' to analyse why three service user groups in Scotland could not achieve full partnership in negotiating about service change (Lewis 2015). For example, as has often been pointed out before, any display of emotion is immediately pathologised as the discourse of psychiatry and the discourse of mental illness are dominant in every exchange. The service user groups could not achieve what Fraser calls 'parity of participation' because the power / knowledge axis of psychiatry positioned them as unable to speak rationally. This is an interesting analysis but not, I suspect one that Fraser herself would accept. The reason I am sceptical is that Fraser never

completely decouples culture from the economy – she is a socialist feminist and concerned with injustices of misrecognition to be sure but always imbricated with injustices of maldistribution (Fraser and Honneth 2003, Fraser 2013). And she is becoming increasingly careful to differentiate her concept of misrecognition from those of identity politics. The argument is very complex and as ever she ignores disability assuming, ironically for my purposes here, that the state will provide. However, I think there is something to learn here in the very new context in which we find ourselves today; that is economic and neoliberal austerity. Since the dawn of the industrial revolution and spanning what Foucault calls the ‘Great Confinement’ (Foucault 2013) to its special form in the Asylum system to community care and the welfare state it has been assumed that the ‘sick and disabled, the unreasonable’ are unable to labour, or at least enter the open labour market. Now, in the last five years or so, the ‘mentally ill’ have become the embodiment of the new ‘scrounger’, positioned anachronistically as the ‘undeserving poor’ whilst and at the same time not working has been psychologised (Perkins and Corr 2005). And this is not happening without opposition, without voice both on the internet and in groups such as the Mental Health Resistance Network. This grassroots activity, especially on social media, is a new form for the survivor movement and I think well captured by Fraser’s theory of injustices of both distribution and recognition. It also fundamentally broadens the parameters of arguments about social injustice beyond psychiatry and indeed recasts its role. Fraser re-frames identity politics through the concept of recognition and renders it more complex by bringing this into relation with economic and political distribution. Thereby she avoids a reductive and essentialist account.

Standpoint epistemology and situated knowledge

It should be clear by now that I am arguing for the privileging of collectively produced knowledge. This to be always in touch with grassroots political activity and its attendant knowledge forms which I think today are being produced in social media more than in conventional meetings. But I am also arguing that there is a specific space for theory and that this space too should be collective. In fact it already is even if sometimes this goes unrecognised: the debates we have and the papers we produce are not the expression of private, individual thought but collective through and through as each contribution is only made possible by previous ones and anticipated ones.

I return first to the emphasis on the collective and the role of political struggle and take as my exemplar discourse that of feminism. Early radical feminists believed ‘women’s knowledge’ could be based on something essential about women – notably, their biology and role in nurturing. The rise of feminist standpoint epistemology saw the argument that a ‘standpoint’ was not ascribed but ‘achieved’ through collective political struggle (Harding 2004). That is, there might be a specific feminist base to knowledge but it was not a matter of individual experience. The idea of ‘standpoint’ also overturned the notion of a single, universal knowledge and a value-free knowledge. The concept of ‘intersectionality’, referred to above, amongst other things drove home this epistemological lesson (Collins 2002). The role of feminist scholars was to use such knowledge to theorise, “study up”, the situation of marginalised groups (Harding 2008). Scholars, too, did not work alone which did not mean enduring consensus.

Standpoint theory has been criticised for being ‘relativist’ – that any theory, indeed any ethics, is possible and there is no way of adjudicating claims between them. Haraway has, in my opinion, answered this critique and she has de-throned the idea of epistemology as such, at least as a ground

for universal truth claims (Haraway 1988, Haraway and Goodeve 2013). Her argument is that *all* knowledge is socially situated. This includes mainstream knowledge which bases its claims for knowledge production on the belief that it is 'value-free' and 'objective'. The problem is that it claims universal knowledge, by virtue of a universal method which posits the 'scientist' as a universal knower when in fact the knowledge thus produced is contingent and partial. This is the 'God trick'. Knowledges which are self-reflectively partial and aware that they are grounded socially are therefore more transparent and 'more objective', characterised by what Harding calls 'strong objectivity' (Harding 1991). Mainstream science, and for our purposes mainstream psychiatry, is characterised by 'weak objectivity' because it hides its value and epistemological bases in such a way as to naturalise and normalise the position of marginalised groups thus making the status quo unquestionable.

Further, there are political grounds for valuing the knowledge of marginalised groups as this has traditionally not been allowed to speak or even be formulated. It follows from this that any claim to produce 'universally true' knowledge cannot hold. This in one sense is the end of epistemology as the search for grounding universal truths. So mainstream science is vitiated by this argument, at least in so far as it follows its own premises. Service users and survivors who are involved in this are constrained from doing anything novel although they are likely adding to the internal strain. If I am even partially correct in my analysis of Mad Studies, then insofar as it believes it has understood the 'fundamental truth' of psychiatry it is making the same mistake as mainstream science. Insofar as it is nourishing a true flowering of diverse discourses, it is at least epistemologically more coherent.

Interestingly, writers like those invoked above are not averse to empirical work. Most are social scientists or work in an interdisciplinary way but Haraway is a molecular biologist and primatologist. She has a long history in HIV/AIDS activism and has now turned her attention to the posthuman. Empirical work can illuminate the situation of marginalised groups as long as it does not make grand truth-claims based on dubious general theories. Similarly, practical and political work is an intrinsic part of this endeavour. It is both its base and part of the challenge it poses to historic ways of organising society and institutions. So new forms of support for people in distress are not an 'outcome' of research and scholarship, they are part of it and if they are lost sight of the former will be diminished.

I have argued strongly for recognition of the collective in both reframing experience through survivor and other organisations and in theoretical work. However, this also has a very practical dimension which I shall address by returning now to the idea of user-controlled research highlighted as an alternative to the PPI model in England at the beginning of this paper. This can mean research, empirical and conceptual, conducted by user-controlled organisations and this should be protected. The obvious difficulty is that such organisations are not well-resourced and the reasons for this include disputes over what counts as valid knowledge. The question I would like to put is whether user /survivor researchers *not* in such organisations are nevertheless partaking in a collective endeavour. My provisional answer to this is that it is possible. Whilst by no means universal, many such user /survivor researchers have strong roots in the user movement, as well as other social movements, and do not leave these at the door of the office in a non-user-controlled space. Others without such a history nevertheless have a strong commitment to social justice. Social media offer an additional and growing space to make these connections. This is an argument for building bridges between survivor researchers and scholars in different settings and foregrounding politics including

working to shift funding priorities. This will entail disputes about what counts as valid knowledge, that is it will engage epistemology as well as, and concurrently, what should change at the level of practice.

Conclusion

In this paper I have tried to engage with four bodies of work at a theoretical level whilst never losing sight of the political. I see a role for intervening in the academy, what in the 1970s we used to call 'theoretical struggle', and hope the paper speaks to each of the discourses implicated. I hope, in particular, to have opened up a space where survivor knowledge can find a place in other critical theories and especially those which have counselled an end to grand theory and universal epistemologies. This is not an argument against the importance of theoretical work, it is an argument that theoretical work should be grounded in and articulate the social and political situations of specific and specifically marginalised groups. Thus this paper has had a double purpose: to use critical theory to assist the articulation of survivor studies and to insert survivor studies into the discourses of critical theory. Finally, I am aware this is a modest contribution to the contemporary struggles of survivors – academia and theoretical work outside it are not the grounding of what we do. However, the distribution of knowledge means that academic spaces are privileged as knowledge-generators and that knowledge is also privileged by policy makers although even that might be currently changing which makes the current political configuration very challenging (but that is a paper in itself). That privilege can be questioned fundamentally from within its dominant sites – primarily the academy – and by creating new spaces where new thinking can emerge. I aim simply to contribute to that questioning without underestimating the institutional and resource difficulties.

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