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Destabilising Equilibriums: harnessing the power of disruption in participatory action research

Abstract

This article draws on insights gained from three projects described as participatory action research (PAR) and undertaken in separate contexts within the UK. What binds them together alongside the commitment to PAR is that each project coordinator raised the issue of the under-representation of opportunities for disruption as a trajectory to knowledge democracy.

PAR places a relational process at the centre of the research practice. It brings together people with varied knowledges, perspectives and experiences and aspires to be a non-hierarchical, relational, collaborative endeavour. This challenge and disrupts the traditional hierarchical hegemony of the external expert in research situations. Bringing people together does not, however, equate to shared agency, authentic participation and knowledge democracy. For different knowledges to be created previous knowledges need to be disrupted. The argument raised in this paper is that a neglected element of PAR has been the deliberate intent to nurture disruption within communicative spaces in relationally based engagements. It is posited that disruption within the PAR process itself, the disruption of beliefs and assumptions that underpin local actions, is an important enabler of other voices and knowledges being recognised and acted upon. Forged by a range of actors the disruption of hitherto accepted knowledge creates a space for new ways of seeing and doing. The three projects described in this paper reveal how and why the recognition of the centrality of disruption, and harnessing its power, contributes to creating a functional knowledge democracy for more radical change.

Introduction

This paper explores how certain elements of the participatory research approach, generally assumed to facilitate a process of knowledge democracy, may limit radical equality and hinder the true democratisation of knowledge. We, the authors, are interested in what aspects of participatory action research (PAR) enable a move from consensus based on dominant knowledges, or shared assumptions about knowledge in action, to allow new understandings to emerge.

The move to more democratic, participatory research approaches has been evident in policy and practice across many cultures and continents (Abma et al. 2019). An express intention of research that falls within the participatory paradigm (for example participatory action research, participatory health research and community based participatory research) is to address power differentials that create health and social injustices. The aim is to effect change through creating spaces for shared learning and connected knowing (Ledwith and

Springett 2010). There is, however, a great diversity among participatory approaches to research in terms of nomenclature, terminology, intention, theory, process, and outcome (Wallerstein et al., 2018; Cook 2017; Ismail 2009) The embedded participation of those with experience and knowledge related to the research focus is, however, the unifying feature.

The primary underlying assumption for PAR is that participation on the part of those whose lives or work are the subject of the study fundamentally affects all aspects of the research (ICPHR 2013, 5). The new knowledge engendered through PAR is produced collectively rather than by an individual or unilaterally by a particular sub-set of individuals. No single form of knowledge, such as academic knowledge or practitioner knowledge, is given primacy over another. It places what Fals Borda (1988) termed “popular knowledge”, alongside the dominant knowledge paradigm. The intention is, through a research process that involves shared engagement in critical reflection, for people to learn with and from each other. Building knowledge is not just a one-way flow, it is a collaborative dialogical model for co-learning (Abma et al. 2017). This collaborative, iterative process is intended to build new knowledge for the purpose of taking social action. Such collaborations have been termed “communities of practice” (Wenger 1998). Communities of practice are the bedrock for PAR and for democratic forms of knowledge mobilisation. The move from the linear to the collective afforded by communities of practice challenges the dominant ways knowledge is produced (Reason and Bradbury 2008). This holds the potential to create spaces where people who may experience endemic social injustice and, what Fricker (2009) termed epistemic injustice, find empowerment. Social justice is concerned with creating fair relations in terms of opportunity between people and society. It is a means of nurturing civil societies through challenging the underlying assumptions that elitism is efficient, exclusion necessary and prejudice is natural (Dorling 2011). Epistemic injustice forefronts the impact of prejudice, particularly the ongoing prejudice that leads to deflated levels of credibility for certain sectors of society. It highlights the lack of shared social resources that makes it difficult for people outside the traditional knowledge brokers to articulate their experience in a way that is recognised and valued (Fricker 2009).

In the UK health research (particularly nationally funded health research) has historically been rooted in medical science. This has taken positivist approaches to addressing questions that matter to professionals involved. The research questions and the way in which data are collected and analysed have been determined by experts distanced from lived experience. Their knowledge and theories have predominated when shaping what questions need to be asked and answered and hence what can be known. In recent years, however, there has been a steady and determined argument for raising the status of forms of knowledge that arise from the experience of those living or working in the arena that is the focus of the research. This is signified by an intention to work in partnership with users of services and the general public on research projects. Epitomised by INVOLVE (an organisation funded by the National Institute for Health Research (NIHR) to support active public involvement in National Health Service (NHS) research, public health and social care research), the vision is to create “a world of active public research partnerships leading to improvement of health and care for all” (invo.org.uk 2018). Approaches that start from creating partnerships would seem highly

pertinent as a basis for participatory forms of research that embrace a more democratic approach to knowledge production for change.

The three vignettes presented in this paper are not reports of projects that set out to investigate the power of disruption. They are reflections, carried out by the authors of this paper, on three projects committed to creating spaces for authentic participation. Authentic participation is defined by McTaggart (1997, 28) as “ownership, that is, responsible agency in the production of knowledge and improvement of practice”. All three projects were rooted in an understanding of action research as a means for mining and generating local, experiential knowledge as a change mechanism. Working alongside each other, knowing each other’s projects, the authors serendipitously formed a community of practice. Through this we reflected on what was revealed by the projects about the capacity of PAR to create spaces for knowledge democracy and radical change, and why radical change may or may not have occurred in our respective projects. In particular we considered the nomenclature or concepts used to describe the approaches to research (co-produced, emancipatory and partnership) and how the usual underpinnings or building blocks for these had not been the key elements that ultimately supported democratic change.

The shift towards recognising the value of more participatory forms of research is underpinned by a range of processes seen as the building blocks for facilitating more democratic approaches to knowledge creation. These building blocks include the forming of communicative relationships, gaining respect, giving voice, sharing skills and raising confidence. Through undertaking the set of research projects presented in this paper we recognised the importance of clarifying the way in which these building blocks are perceived and developed, what their purpose might be in a participatory action research paradigm, and whether they are sufficient to mobilise new knowledges for change. We suggest that adopting these descriptors, without rupturing or destabilising their common conceptualisation and use, can perpetuate traditional forms of knowledge production and may well contribute to an illusory perception of the development of knowledge democracy through the participatory paradigm. We argue the need to disrupt familiar, habitual understandings, and use, of processes considered to be facilitatory of knowledge democracy. If the inclusion of experiential knowing in communities of practices is, as Kolb (1984) suggests, a lynchpin for change in practice, then we need to consider how we use the building blocks for PAR. We ask what needs to be disrupted to enhance the use of, not just experiential knowledge, but all knowledges, as positive mechanisms for advancing democratic approaches in both research and practice.

Outline of the article

We begin with a vignette that recounts the experience of engaging in a mental health recovery research project, funded by the UK NIHR. Through this the authors, Brandon and Thomson, explore the practical and conceptual application of research as disruption in relation to building researcher knowledge and capacity. At the core of this work was a drive for co-production between service users, family carers, academics and professionals. Hierarchies that

traditionally reinforce power relationships within research were challenged and continually reconstructed throughout the life of the project. What became questionable, however, was whether the disruption went far enough to challenge the underlying undemocratic dynamics which govern research and the practice world in which it sits. Were they still complicit in reinforcing old hierarchical roles and power-based research values upon new researchers?

Next, through her doctoral study, investigating the effects of a new social policy in the UK, Maryam Zonouzi explores how current paradigms of emancipation can inhibit radical equality and present a barrier to the true democratisation of knowledge. She describes work of a group of UK disabled researchers who sought to empower themselves through a research approach to re-structuring services. From this she argues that emancipation, as it is commonly and globally defined, runs the risk of perpetuating the power differentials and knowledge hierarchy that inhibit knowledge democracy and social justice. The experience of carrying out first, action research (AR), then PAR and finally what they termed Radical Dissensual Research (RDR) became the starting point for constructing a space to challenge, disrupt and reframe hegemonic thinking.

The final vignette brings to the fore the centrality of partnership models and the need to recognise how underpinning building blocks match the espoused meaning and purpose of partnerships in PAR. Partnership models appear to offer opportunities for collaborative rather than a professional led research design. Based on a study also funding by the UK NIHR, Tina Cook, suggests that an enactment of the dominant concept of partnership, framed and led by those who traditionally hold power, rather than being facilitative of knowledge democracy, can, however, present a barrier to its development. Partnership working, generally conceptualised as a means for facilitating democratic and inclusive engagements, can underutilise, and at worst be destructive of, democratically based research.. An approach to partnership working that creates a space disruptive of rhetoric and common consensus, is placed at the heart of the democratisation of knowledge.

Study one: Recovery and Care Co-ordination: challenges for co-production as knowledge democracy in mental health research

Background

The history of mental health research follows the dominant paradigm of the medical model (Goodley, 2011). The medical model is fundamentally a positivist approach. It understands and treats mental distress as an illness located within the individual. This distress is characterised as a problem to be solved by others who present as experts. In the last twenty years this position has been challenged by a movement of disabled people hailing ‘nothing about us without us’. From this position new research methodologies grew that challenged this medicalised approach (Barnes and Mercer 1997). Such methodologies value the voices of mental health service users and carers as experts in research and as a route to changing the value base for knowledge use. More recently the discipline of Mad Studies (LeFrançois, Menzies and Reaume 2013; Spandler and Sapey 2015) has grown to incorporate holistic socio-political progression in theorising mental health. This challenged the view of people with mental health distress as having less

value and the need for distance between their direct experience and the interpretation of that experience (Beresford 2016). From these positions came a push towards the democratic co-production of knowledge within mental health.

Within this spirit of co-production, a local (North East of England) mental health service user forum was approached by Brandon, a university academic with close links to the forum, and asked what they considered important to research. The issues most pertinent for them were around recovery and the application of care co-ordination. Recovery, a commonly used term in mental health service delivery, was chosen because it can be used to challenge the negative assumption that mental distress is an incurable lifelong condition. It is, however, a conflicted term, it being unclear what people are recovering from or to in relation to their mental health and personal well-being. Care co-ordination was chosen because of its central role in the design/delivery of services (DoH 2008) and its potential to be an integral part of people's recovery journey.

Project design: spaces for change

The Recovery and Care Co-ordination (RCC) project took place in a large NHS Trust delivering mental health services in the UK. It was designed around three phases combining both quantitative and qualitative methods (Delphi questionnaire, interviews and workshops) to create action research cycles with Brandon as facilitator. All stages of the work from its design, data collection through to data analysis and dissemination were the joint responsibility of the academics, practitioners, service user and carer researchers involved. The second phase, where mental health service user/carer researchers interviewed selected service user and carer participants about their experiences and understandings of recovery and care co-ordination, is discussed here.

To enable those new to research to take a meaningful role within the process a university accredited mental health research training course was offered. This developed research skills but also provided the basis for building important relationships within the team. One researcher involved commented on this sense of involvement:

The team building obviously benefitted from the time devoted to training. There was a sense of common purpose, a privilege to be asked to contribute and have our knowledge and experience valued.

Louise Thomson (author) was one of the people who completed the mental health service user research training course and became a researcher on the project.

Whilst participatory in intent, reflections upon the research approach surface issues around the pursuit of knowledge democracy. Firstly, the research training was, in part, delivered by experienced mental health service user researchers yet it followed what might be considered traditional research pedagogies. It was important that people were trained by 'top' people in their fields; however, this training, whilst entered into with a shared commitment to

developing understandings, was not pitched to challenge the dominant voices in knowledge production. In this way it missed out on exploring the agency of the new researchers in a more radical way. In addition, the training was assessed using a written essay requirement. This meant that acquired knowledge was not judged in creative ways that could capture the personal interpretation of what non-traditional researchers had learnt and could contribute. Nor did it afford ways of critiquing the approach to knowledge production being offered, an approach that might inherently militate against the surfacing of different knowledges. The word *training* implies passivity in those being trained, missing the mutually shared production of knowledge that could enhance learning and change.

Secondly in terms of chosen identities, the term researcher rather than co-researcher or peer researcher was decided upon. Some researchers with mental health service user or carer backgrounds did not want to be seen as different from established researchers. Similar to disabled people “passing as” non-disabled in an attempt to avoid stigma and discrimination (Cameron 2013) it can be argued that there may be a desire to blend in, have equal status and “pass” as academics. Hutchinson and Lovell (2012, 647), in their participatory research, stress the importance of these kinds of shifts in identity. “We have moved from being service users, to being researchers, a positive identity, which has motivated us all, yes we are useful...” Acquiring a new identity which increases agency can be significant in people’s lives. If, however, the status and types of knowledge carried by the academic researcher remain unchallenged, are people just adopting the mantle of the academic researcher and leaving the research approach undisturbed? This researcher recognised this issue but articulated an alternative view. They saw the importance of having their service user perspective clearly recognised.

I don’t really feel researcher is an ‘upgrade’ on service user researcher. I wouldn’t have got involved in this research but for my experience of using services after all and if I were on the lookout for further work of this kind, experience of being a service user would still be the advantage I’d have over other candidates...That name in my opinion has nothing to do with the level of skill I possess as a researcher after all.

Reflections

The RCC project set out to challenge hierarchies of traditional project relationships and to mobilise the knowledge and voice of service users and carers. Reflections on this project prompted the question: did the design and research training at the core of this project merely perpetuate a culture that avoids challenging inherent undemocratic acquisition of knowledge? On the positive side, the traditional allocation of boundaries between the researcher and researched, the manager and the managed were disrupted by sharing responsibilities. As one new researcher commented, the training and the research design went some way to demystifying the role of the academic researcher.

Just giving a voice to the service users and carers we interviewed and showing that we valued their perspective instead of doing research on them is a positive step. I like to believe that as service users and carers our own personal stake in

improving services made a huge impact on the interviewing, data analysis and importantly dissemination.

It is, however, unclear exactly how much, in the desire to aid the emancipation of service users and carers, the new researchers were led into a professional researcher role shaped by academic traditions that reinforced non-progressive systems. The way research is designed influences the voices that can be heard and the sets of knowledge that are valued. Unchallenged commodification of knowledge can maintain marginalised identities and limit democratisation. This researcher expressed the importance of creating the space to bring different knowledges to their own positioning:

The advantage I feel I have at this point in my life is that I am valued, rather than pathologised by my experience in services...Being able to talk, when relevant, about my experience of services has been affirming on the whole, though also emotionally challenging at times. I'm also aware of the limit to my service user experience. No one person's experience is the same as another's, so I can only speak for myself, while taking a great interest in hearing from others.

The RCC project did have impact. Its findings were accepted by the NHS Trust hosting the research and practitioners in the research team were invited to embed those findings into care co-ordination pathways. However, despite the influence non-traditional researchers undoubtedly had on what could be known through this project, the question remained as to whether being trained to adopt traditional research methods limited what could be known and by default limited what radical change could be effected in service delivery? Resisting replicating the presentation of unchallenged hierarchies for research methods and exploring new narratives around the value of different ways of generating knowledge and what being a 'proper' researcher might mean, could promote more radical change in the future. Working together per se is no guarantee of democratic change in co-produced research. Learning from the RCC project would be that, in this case, it did not go far enough in mobilising different knowledges that could destabilise underlying undemocratic dynamics. Opportunities for co-production to disrupt hegemonic knowledge generating processes were limited by the unreconstructed adoption of traditional research approaches.

Study Two: Self – Directed Support: Disrupting Notions of Emancipation

Background

In 2008 a new policy, Self-Directed Support (SDS), was introduced in the UK. The intention of this policy was to put disabled people in control of their own support arrangements. It transferred care decisions and financial control over personal care from welfare professionals and state agencies to disabled people. The focus was on “giving people real power and control over their lives” (<http://www.incontrol.org.uk/support/support-for-individuals,-family-members-carers/what-is-selfdirected-support.aspx>). Wresting control over their own care from welfare professionals was considered an important mechanism by which disabled people might

find empowerment and emancipation, something the UK disability movement has long campaigned for.

The UK government directed local authorities to establish a Centres for Independent Living (CIL) in each locality by 2010. A CIL is a user-controlled organisation which supports disabled people to live independently in their communities. Led by the Chair of the SDS Board and doctoral researcher, Zonouzi, a group of disabled people, all of whom had enthusiastically opted into SDS, wanted to investigate the implementation of a CIL for SDS and whether it resulted in empowerment and emancipation for disabled people. The CIL, rather than being controlled by external agencies, would be controlled and managed by disabled people and disabled people would also be trained as peer support brokers to help others manage their SDS budgets. The question was whether, and how, transferring power from welfare professionals to disabled people emancipated (freed) disabled people from professional power and produced empowering outcomes and whether independence, choice and control were catalysts for empowerment.

Empowerment and emancipation are commonly used terms in the disability movement. Empowerment is defined as *power to* (the ability of disabled people to make their own choices and decisions) and *power from* (where disabled people take power from those who are seen to oppress them). Emancipation is defined as *freedom from* (oppression) and *freedom to* (exercise choice and control). If emancipation is only achieved when disabled people are free from professional oppressors, this posits a fundamental inequity between disabled people and the professionals in the welfare system. This conceptualisation of emancipation would seem to be problematic for an understanding of knowledge democracy predicated on equality rather than hierarchical inequality.

The SDS study had three parts. The first part used an action research (AR) approach. The second part, initiated as a consequence of issues revealed by the AR study in both the research and the actions taken, took a participatory action research (PAR) approach. The third stage adopted an approach that was termed Radical Dissensual Research (RDR) as a consequence of the learning from the first two stages.

Part 1: Action Research and the Emancipatory Disability Paradigm

An AR approach, led by Zonouzi, was combined with the principles of the Emancipatory Disability Paradigm (EDP) (Oliver 1997; Barnes 2003), to investigate the best way of implementing SDS. EDP is defined as “the systematic demystification of the structures and processes which create disability” (Barnes 1992 cited by Barnes and Mercer 2004:121). It starts from an assumption that disabled people require support, through consciousness raising, to become self-determined.

Disabled people involved in the project wanted to take control of their own care budgets. They saw SDS as a way of becoming more independent. AR afforded a systematic approach to researching the impact of SDS on their lives. Focus groups, designed and led by

Zonouzi, were thus carried out with the disabled people involved in the CIL. Data from these showed that people, far from feeling emancipated by being in control, were feeling overwhelmed by the responsibility of managing their own care and support. They did not feel empowered or emancipated but oppressed and weighed down by the burden of taking control from welfare professionals. Brokers reported feeling like gate keepers. Disabled people reported that peer brokers were exerting power over them in the same way as the welfare professionals before. The transfer of responsibility had perpetuated a power dynamic that focused on the co-option of *power over* without disrupting the structural conditions of power or empowerment. Thus, the underlying premise of power and empowerment within EDP was exposed. The wresting of *power over* from one oppressive hierarchy and transferring it to another (disabled people themselves) left disabled people feeling doubly oppressed.

Reflection on this insight into practice also offered an insight into the research design. Whilst the participants were willingly involved, the lead researcher had shaped and framed it. She had exerted *power over* the research process. If an assumption of equality was the starting point, how did a research approach that used the construct of the leader and the led, facilitate this? Did the co-option of participants (however willing) into research, led and designed by one researcher, the Chair, mean it started from a position of inequality? Had AR been used as a technical approach to investigating the best way of supporting co-researchers to implement the SDS policy, unchallenged into their lives whilst retaining its underpinning hierarchical structure, a process which ultimately reinforced existing hegemonic thinking around power and empowerment, independence and emancipation in the research situation? Recognising the implications and limitations of AR meant it became important, not only to disrupt and overturn the conceptual underpinnings of the social policy being implemented, but also the research approach being used to investigate it.

Part II: Participatory Action Research (PAR)

PAR starts from a point where all engaged share responsibilities for deciding how to fundamentally critique theory and practice. The next phase of the research adopted a critical PAR approach. This provided the space for Zonouzi, and disabled people involved in the development of the CIL, to work together to co-design a more discursive approach to focus groups. This time Zonouzi took a more facilitative approach, supporting conversations that enabled all concerned to better understand the impact of the new structures for taking control of the SDS process. Critiquing the way in which control had been transferred to the CIL for SDS surfaced the fundamental issue that freedom *from* had only created new power structures. This challenged the hegemonic conceptualisation of taking control through adopting the mantle of the previous system. This had only led to disabled people having to wield power over other disabled people. Hierarchical conceptualisation of emancipation needed to be rooted in ‘disruption of’ systems rather than ‘freedom from’ a particular dominant group. This applied to emancipation in terms of policy implementation and the research approach. If all knowledges were to be mobilised, there needed to be a “rupture in the order of things” (Biesta 2010, 32). A new research approach fore fronting both disruption and equality emerged from our reflections to serve this conceptual shift. We termed this Radical Dissensual Research (RDR).

Part III: Radical Dissensual Research

RDR presupposed a radical equality between those traditionally thought of as knowledge and power-poor and those previously cast as experts. As in PAR, the starting point of collaboration and knowledge co-construction was a shared learning approach, but, having revealed through the first two parts of the research that *power over* was not a route to emancipation, RDR made explicit the commitment to disrupting given knowledges and hierarchies rather than merely adopting them. The research process became a process of critical reflection with the specific intention to disrupt current systems rather than take control. In this way all those involved became active in disrupting previous ways of ways of conceptualising, ways of knowing and ways of acting. The outcome being that, through the experience of re-conceptualising the meaning of emancipation, the structures and processes for the CIL, SDS and the research approach, were directly connected to reframing, rather than taking control of, established practices.

Reflections

What was learnt from this critical participatory approach was that emancipatory politics was not about disabled people coming together to aggregate opinions and form a consensus but that it occurred when disruption of those opinions and understandings become manifest. It involved interrupting current ways of thinking and challenging the logic of certain, dominant ideas. In this study disabled people had thought they wanted to take the power from professionals to manage their own care. When this was achieved they reported that they were not now empowered but burdened taking on the same mantle of power as the professionals. The AR/EDP research approach had emphasised and consolidated this burden. Whilst devised and facilitated by disabled people they had used the flag of knowledge democracy to raise one community of people above another. This could not be understood as democratic. Thus, the underlying premise of the transfer of power as empowerment within EDP was exposed. Classical conceptualisations of emancipation contain the binary of power over. This was recognised as an internal incoherence that lead to the re-creation of oppressive systems of hegemonic thinking. Disrupting the hegemonic consensus was a pathway to a new, more democratic approach, to knowledge construction. Knowledge mobilisation developed when ordinary people disrupted both their own thinking and actions alongside that of distant experts. This disruption was the demonstration of knowledge democracy in practice.

Family Based Positive Support (FaBPos): Disrupting notions of partnership

Background

Drawing on the principles of Mindfulness and Acceptance and Commitment Therapy (ACT) (Noone and Hastings 2010) the aim of the Family Based Positive Support (FaBPos) project was to understand the core components for an effective course for family carers of adults with learning disabilities and behaviour that challenges. Family carers are likely to suffer long-term stress caused by the unpredictable, and often socially difficult, behaviours of their loved ones. There are very few services to support them. Where families have had contact with services there tends to be an unsatisfactory history of engagement that has created tensions between carers and professionals. Family carers in the FaBPos project generally characterised services

as distanced, bureaucratic and unresponsive with professionals who did not take sufficient time to try and understand their lives and needs. This contributed to their stress.

A lack of appropriate services to support family carers in their caring role was the impetus for a partnership approach for researching and constructing a course that would be effective in building resilience. The aim of the FaBPos project was to bring together the knowledge and experience of deliverers of services (psychologists) with the knowledge and experience of receivers (family carers) to research the key elements for an effective course. This held inherent tensions given the negative experiences of family carers with previous engagements with services and the power dynamics created by professionals being seen as gatekeepers to knowledge and services. The challenge for the FaBPos partnership was, as Bergold and Thomas (2012) suggested, to create safe spaces where critique could take place, where differences of opinion were permitted, revealed and jointly discussed

A key element of the project was to avoid replacing one knowledge set with another, whether that was professional knowledge or family carers' knowledge. Learning together was seen as the vital element for mobilising knowledge for change. At least two disruptions were needed to achieve this.

- i) Disrupting traditional hierarchical expectations about whose knowledge counts.
- ii) Disrupting the concept of partnerships as places for debate and consensus with the notion of critique for learning.

Designing spaces for critical reflexive practice

Partnerships have been conceptualised as a “respectful, negotiated way of working that enables choice, participation and equity within an honest trusting relationship based on empathy, support and reciprocity” (Bidmead and Cowley 2005, 208). The positioning of partnerships as somewhat benign spaces can, however, as Ballock and Taylor (2001, 2) suggest, hold the potential to “...underplay the difficulties in bringing together different interests and different cultures”. Struggles with services over many years had led family carers to see professionals as unwelcome and unhelpful intruders into their lives. Before designing the basis for a FaBPos course and associated research process, therefore, a year was spent talking with family carers about their experience of services, what they might hope for to support them in their caring role and what might motivate them to take part. The project design team (PDT) (three family carers, a clinical psychologist with a wealth of experience using Mindfulness/ACT and a university academic with experience as a practitioner working with family carers and experience with of engaging in participatory health research) then used this information to design both a course outline and a research project that would address issues raised by family carers in a way that made them feel comfortable enough to participate.

The underpinning design for the research was a series of three courses of Mindfulness/ACT, hosted by Noone (an NHS senior clinical psychologist) in non-NHS venues where family carers would feel more comfortable. Each course consisted of 5 sessions of Mindfulness/ACT and, facilitated by Cook, an academic researcher who also has a background as a practitioner working with people with learning disabilities and their families, embedded

spaces for relationally-based dialogical engagements (communicative spaces). This form of discourse involved the critical examination and evaluation of thinking and knowledge as it occurred. It offered the potential to mobilise new and tacit knowledge through what Habermas (1998, 159) termed a “shared willingness to consider one’s own conditions through the eyes of the stranger, and to learn from one another”. In these spaces diverse knowledges were openly discussed and understandings shared, critiqued and revisited as the course progressed and were the key means for seeing in new ways. This created the basis of a PAR cycle where everyone involved shaped the design and content of the course and ongoing research approach, generated data, made meaning from that data (data analysis) and conceptualised new ways of acting.

Prior to the start of each course recorded interviews with consented family carers and course facilitators were carried out by the academic researchers to ascertain current understandings of life or work situations, roles, expectations of the course and what would signify the success of the course for them. 18 family carers, 3 facilitators and 2 academic researchers took part.

Critical enquiry as disruption

To design a new way of effectively supporting family carers, and to understand how such a course might work, new approaches were needed. Merely creating a relational space for tabling current knowledges, be that the knowledges of family carers or facilitators, could build consensus for acting on what is already known and would not lead to the production of new knowledge. Consensus was likely to be driven, implicitly and explicitly, by professionals. Without professional learning and change it was unlikely that the FaBPos course would address some of the issues that have, in the past, led family carers to perceive professionals as “all give and no take” (FC¹: 1) It was important that those whose knowledge traditionally dominated were challenged by other knowledges in order to “improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out” (Kemmis and McTaggart 1988, 5). This needed careful introduction given the power base of professionals. The need to be critical was therefore introduced to family carers, at the start of each course, in a way that built on their desire and motivation, espoused in the pre-course interviews, to help other families in similar circumstances. If they were not honest about how the course was working, and said things were fine when they were not, it would perpetuate the cycle of family carers coming to ineffectual courses. Framing the project as a way of supporting future families motivated those who might be nervous of being seen as critical of those they perceived as having expertise or power over them, to make their voices heard. Giving the responsibility for the critical enquiry and shared creation of the new course to all those involved was described by this family carer as crucial “you don’t know how important this is” (FC 2). From the very first session of the course family carers and facilitators engaged in critique of the programme and its facilitation.

Disrupting knowledges

¹ FC: Family Carer

The key intention of the Mindfulness/ACT course was to disrupt established behavioural responses to stressful situations. Unless family carers could find a way of changing their response behaviours to stressful situations, then stress would be perpetuated. The set of techniques used (breathing exercises, metaphors to aid self-reflection, Mindfulness tasks) were the tools of the course, but without appropriate facilitation family carers would not have built their own ways of using them.

At the start of the course the facilitators, whilst committed to a listening approach, had an outline curriculum they hoped to present. Family carers were immediately critical of this approach. Initially they just knew it was not working for them but were not able to articulate why. As the sessions progressed, however, through the process of iterative reflexive critique established by the PAR process, facilitators and family carers unearthed the root of the issue and key element that made facilitations effective.

What has been different here is that it is not all give [from facilitators] and take [by family carers] we've not been told. We have done it in this group – everyone has chipped in and we find out from each other. (FC10).

Fundamental to building knowledge about facilitative processes had been the confidence of family carers to engage in critique with the professionals.

One of the big breakthroughs with this is ... doing it together, because what we've ended up with is different from what we started off with... we've created something that none of us would have thought of if we had not gone through it... It's so easy for us as professionals to think these are the latest psychological benefits. We should make them available. Which is, you know, a decent start. But how you go about making them available is you do unto them. I think one of the things that we've learnt in this course is you don't do unto them. That's so crucial. So, dismantle the doing unto. (Facilitator A)

Facilitators recognised that disrupting their own approach had been key to the success of the course. As Cook (2016, 89) suggested “to let go of some of your own ideas/beliefs about working practices...is not easy for any party” but their willingness to consider their own ways of acting, in the light of the way other experienced that practice, led them to personal epiphanies:

In that forum, people were really candid about their experiences...that made me reflect on myself as a practitioner....It makes you then reflect on your practice and, I guess, help you think about what sort of professional you do want to be. (Facilitator B)

These insights led Facilitator B to take these messages back to the wider team to use as principles when working with families more generally.

Reflections

Positioning partnership beyond a place for respectful debate of tabled knowledge towards a place for critique and challenge, where critique and challenge were reframed as difficult, but not disrespectful, disruptive but not discourteous, ways of learning rather than maintaining the status quo, had unexpected and positive consequences for all those involved in the FaBPos project. Ways of reframing practices grew from the deliberate intention to disrupt habits for acting that had become professional, or experiential, wisdoms.

This partnership had not, however, disregarded the building blocks commonly alluded to in partnership working (communicative relationships; respect; giving voice; sharing skills; raising confidence). It used them as the foundations that enabled disruption to occur. Social relationships were paramount for building spaces for critical enquiry that could disrupt knowledge monopolies in a constructive manner. Without these building blocks disruption could have added to the schism between professionals and family carers. The acceptance of critical enquiry as central to the partnership working became a powerful tool for facilitating a course where the knowledge and collective learning of professionals and family carers created new ways of acting and cemented good relationships. To truly understand how a course might work, to design new approaches, knowledges had to be disturbed rather than maintained.

Discussion: building on the critical

The projects presented in this paper did not set out to study the impact of disruption in the practice of PAR in relation to knowledge democracy. Reflecting on our different projects, however, we recognised that where external norms were left undisturbed, particularly norms that valued professional or academic knowledge, this had implications for the mobilisation of other knowledges. Various players in the projects were inhibited by such external norms, both perceived and real. This had an effect on what could be known, on knowledge mobilisation and the potential for change. A critical approach to enquiry has been widely evident in the action research literature over the past 50 years. Carr and Kemmis (1986, 135) stated that if social science fails to recognise that the “subjective meanings that characterize social life are themselves conditioned by an objective context, that limits both the scope of individuals’ intentions and the possibility of their realization”. If we adopt “an epistemology for the process of self- understanding that excludes critically questioning the content of such understanding, the interpretive approach cannot assess the extent to which any existing forms of communication may be systematically distorted by prevailing social, cultural or political conditions” (Carr and Kemmis 1986,135).

Questions emerged from our reflections on these three different projects about whether the use of certain descriptors for social research might mask a lack of change. Were such terms being used as an indicator for processes that mobilised new knowledges without delving more deeply into whether this was being enacted in practice? The words used to describe our work, (co-production; emancipation; partnership; PAR) are descriptors innately perceived as more democratic processes for knowledge production. Wearing the mantle of emancipation, without disrupting frameworks that create power imbalances, can perpetuate the role of the hegemonic.

For knowledge democracy, dialogue has to be moved from a unilateral win-lose power conflict to what Torbert (2013) recognised as mutual understanding and mutual transformative power between groups. Bunders et al. (2010, 141) suggest that how well we respond to the challenge of bringing knowledges together “will determine the quality of the research results for both the societal and scientific praxis”.

Each of the three projects presented addressed some of the realities faced by researchers working with communities to develop democratic research processes for social action. Each recognised the need to disrupt long held beliefs and understandings as a means of providing creative spaces to develop new ways of acting and to engage in a critical evaluation of the change processes afforded within projects. The challenges of setting up a critical space for mutual learning highlighted the need to reconnect form with function in ways that recognise how research practices, thought to be drivers for social justice, may perpetuate rather than challenge existing hierarchies for knowledge construction. The reflections undertaken in our serendipitous community of practice led us, the authors, to recognise disruption as a critical element in facilitating authentic knowledge democracy.

Reaching down to the fundamental values of what it means to co-produce, to develop emancipatory practice, to work in partnership, the first step for PAR is the opening of communicative spaces that bring knowledge holders together. Into this space we place critical enquiry as the trajectory to deeper knowing and the turn to disruption. Bringing about disruptions in thinking is “critical to providing points in research that can prick our usual understandings and provide new insights” (Abma et al. 2019, 141). Without the disruption of dominant knowledge, personal, professional or cultural, the danger is that change strengthens the power of those dominant knowledges in shaping practice.

To strengthen the impact of PAR for democratic knowledge mobilisation, and to fulfil its potential to affect the dominance of existing hierarchies for knowledge production, our contention is that the concept of disruption needs to be explicitly positioned in research design, expectations and accounts of participatory research. This positioning elevates disruption from a tacit to an explicit element, placing it alongside, and with, the accepted and expected building blocks for relationally based enquiry for democratic change. Recognising disruption as a necessary driver in participatory research processes is central for enhancing knowledge mobilisation and development. For knowledge democracy to find its place, to make a difference to current systems, there is a need to go beyond tabling our individual knowledges as a hierarchical process and recognise the need for disrupting those knowledges as a shared learning process. This is not a passive act but a radical engagement with the ‘need to disrupt’ as a central element for addressing traditional power imbalances and building pathways for democratic change. Disruption of powerful systems necessitates the production of new narratives that involve those who are already in places of power working alongside those whose voices have not been heard, have been under-represented, or have been heard without agency.

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References:

Abma, T.A., S.J Banks, T. Cook, S. Dias, W. Madsen, J. Springett, M.T. Wright. 2019 *Researching for Change. Participatory Approaches for Health and Wellbeing*. Germany, Springer.

Abma, T.A., T. Cook, M. Rämngård, E. Kleba, J. Harris, N. Wallerstein, 2017 “Social Impact of Participatory Health Research: Collaborative Non-Linear Process of Knowledge Mobilisation.” *Educational Action Research* 25 (4): 489-505.

Ballock, S. and M. Taylor. eds. 2001. *Partnership Working: Policy and Practice*. Bristol: Policy Press.

Barnes, C. and G Mercer. 2004. “Theorising and Researching Disability from a Social Model Perspective”. In *Implementing the social model of disability: Theory and research*, edited by C. Barnes and G. Mercer, G. Leeds: Disability Press.

Barnes, C. 2003. What a Difference a Decade Makes: reflections on doing ‘emancipatory’ disability research. *Disability and Society*, 18 (1): 3-17.

Beresford, P. 2016 “The role of survivor knowledge in creating alternatives to psychiatry”. In *Searching for a Rose Garden: challenging psychiatry, fostering mad studies*, edited by Russo, J. and Sweeney, A (eds) London: PCCS Books

Bergold, J. and S. Thomas. 2012. Participatory Research Methods: A Methodological Approach in Motion *Forum: Qualitative Social Research* 13 (1): Art. 30

Bidmead, C. and S. Cowley. 2005. A concept analysis of partnership with clients. *Community Practitioner* 78 (6): 203–208.

Biesta, G. 2010. A new logic of emancipation: The methodology of Jacques Rancière. *Educational Theory*, 60 (1): .39-59.

Bunders, J.F.G., J.E.W Broerse, F. Keil, C. Pohl, R.W. Scholz and M.B.W. Zweekhorst. 2010. How can transdisciplinary research contribute to knowledge democracy? In *Knowledge Democracy: Consequences for Science, Politics and Media* edited by R Jaap in 't Veld 125-153 Heidelberg: Springer

Cameron, C. 2013. *Disability Studies: A Student's Guide*. London: Sage

Carr, W, and S. Kemmis. 1986. *Becoming critical. Education, knowledge and action research*. Lewes: Falmer.

Cook T, Boote J, Buckley N, Vougioukalou S & Wright, M (2017) Accessing Participatory Research Impact and Legacy: Developing the evidence base for participatory approaches in health research. *Educational Action Research* 25 (4) pp473-488

Cook, T. 2016. Working at the intersection: partnerships as participatory mechanisms for disruption: In *Teacher Education in Challenging Times: lessons for professionalism, partnership and practice*, edited by J. Moore and P. Bamber. eds 83-93 Abingdon: Taylor and Francis

Department of Health. 2008. *Refocusing the Care Programme Approach: Policy and Positive Practice Guidance*. London: Department of Health.

Dorling, D. 2011. *Injustice: why social inequality still persists*. London: Policy Press

Fals-Borda, O and M. A. Rahman 1991 *Action and Knowledge: Breaking the Monopoly With Participatory Action Research*. New York: Apex Press.

Fricker, M. 2009. *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press.

Goodley, D. 2011. *Disability Studies is an interdisciplinary introduction*. London: Sage

Habermas, J. M. 1998. *The Inclusion of the Other: Studies in Political Theory*. Cambridge: The MIT Press.

Hutchinson, A. and A. Lovell. 2012. Participatory action research: moving beyond the mental health 'service user' identity. *Journal of Psychiatric and Mental Health Nursing* 20 (7): 641-649.

International Collaboration for Participatory Health Research. 2013. Position Paper 1: What is Participatory Health Research? Version: Mai 2013. Berlin: International Collaboration for Participatory Health Research. <http://www.icphr.org/position-papers/position-paper-no-1> [Accessed 20. March 2018].

INVOLVE. 2018 About INVOLVE [invo.org.uk: accessed 25.April 2018]

Ismail, S. 2009. Participatory Health Research. *International Observatory on Health Research Systems*. Cambridge: RAND Europe.

Kemmis, S, and R. McTaggart. 1988. *The action research planner*. Geelong: Deakin University Press

Kolb, D. A. 1984. *Experiential learning: Experience as the source of learning and development* (Vol. 1). Englewood Cliffs, NJ: Prentice-Hall.

LeFrançois, B. A., R. Menzies and G. Reaume. eds 2013 *Mad Matters: a critical reader in Canadian Mad Studies*. Toronto: Canadian Scholars' Press

Ledwith, M. and J. Springett 2010 *Participatory Practice: Community-Based Action for Transformative Change*. Bristol UK: Policy Press.

McTaggart, R. 1997. "Guiding Principles for Participatory Action Research" in *Participatory Action Research: International Contexts and Consequences*, edited by Robin McTaggart, 25-44 Albany: State University of New York Press.

Noone, S. and R. P. Hastings. 2010. Using acceptance and mindfulness-based workshops with support staff caring for adults with Intellectual Disabilities. *Mindfulness*. 1 (2): 67-73.

Oliver, M. 1997. "Emancipatory Research: Realistic Goal or Impossible Dream". In *Doing Disability Research* edited by C. Barnes and G. Mercer. 15-31. Leeds: The Disability Press.

Reason, P. and H. Bradbury eds 2008. *The Sage Handbook of Action Research: Participative Inquiry and Practice*. California: Sage.

Spandler, H., J. Anderson and B. Sapey. 2015. *Madness, distress and the politics of disablement*. London: Policy Press

Torbert, W. (2013). Listening into the dark: Essay testing the validity and efficacy of Collaborative Developmental Action Inquiry for describing and encouraging the transformation of self, society, and scientific inquiry. *Integral Review*, 9 (20): 264–299.

Wallerstein, N., B. Duran, J. Oetzel, and M. Minkler eds 2018. *Community-Based Participatory Research for Health: Advancing Social and Health Equity*, 3rd edition, San Francisco: Jossey-Bass.

Wenger, E. 1998. *Communities of practice: Learning, meaning, and identity*. Cambridge University Press.