

Peter Beresford

Community Participation in Research: from paradigms to practice

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Valuing direct experience: a basis for renewing research

My contribution today is primarily about first hand experience and its potential role and central importance in the construction of knowledge. My underlying point is that we must engage with the diversity of experience if we are to address diversity in research, otherwise all we are likely to do is to mirror prevailing exclusions. This includes diversity in all its senses, addressing equality issues, differences in communication and people's access issues.

First hand experience is important in my work life. While I work in a university as an educator and researcher my personal experience as a user of mental health services has encouraged, not to say sometimes forced me to pay particular attention to personal/direct experience and as a result this interest has crossed boundaries and entered into my work and plays a particular part in it.

I want to draw on two case examples today; one of them is war the other is madness and distress or what tends to be called now mental health problems. The two of course have many intersections. We are interested today in communities. War divides and destroys

communities and people with mental health problems can expect to be excluded from communities. I hope you won't feel by my choice of case studies that I have wandered away from our focus, I don't believe I have, but forgive me if I seem to, to start with.

There's a strange irony in the fact that war, perhaps the event and experience that most crushes and destroys human beings, also seems to be the arena where in a hierarchical and excluding world, we are most likely ultimately to be able to become acquainted with and share the experience of 'ordinary people', whose experience we might not usually encounter.

Next year is the one hundredth anniversary of the beginning of the first world war, 1914. I don't know how this is with the other nations involved, but certainly a big fuss is being made about this in Britain. Already Prime Minister David Cameron has highlighted significant sums of public funding to be spent on commemorating this event and conflicts are emerging about how exactly we should be remembering this watershed in our history – the first international truly mechanized mass slaughter of people.

As I have said, this may all seem a long way away from the planned focus for today, but I want to suggest it is far from it. In recent years, there have been strong moves to reinterpret the first world war/world war one, or the Great War as it was originally called. There have been growing calls that it has been misunderstood and misremembered. The view of it that grew and took root in the 1960s

that it was a terrible waste; that millions died unnecessarily and that we could best understand it through the words and experience of the famous great war poets – Owen, Graves, Sassoon and others – has been challenged. A classic example of this revisionism is Corrigan's *Mud, Blood And Poppycock*, described on the dust jacket as 'A clear, crisp, highly readable narrative', by the Daily Mail – who else?

Instead such historians have argued that it was a sad but necessary war, it had to be fought to stop German imperialism; that the military commanders did the best they could, that we have got it all wrong to understand it as futile, dominated by military incompetence and the waste of a generation. It was a necessary, grim but properly conducted episode is the message. All else is twenty twenty hindsight and the famous poets whose accounts we have taken as gospel were just a narrow group of public school boys from the officer class, a privileged few, who certainly did not speak for the nation.

We can expect this conflict of opinion to be rehearsed loudly next year in the centenary. Given the dominant politics of Britain, we can expect the revisionist view to be sold powerfully and perhaps to overshadow other humanistic understandings that have seen the great war as a terrible and unnecessary tragedy.

But I want to look beyond these shores for an understanding of that war – indeed to the main enemy we in Britain fought - Germany. Because the best known book in the English language about the Great War was in fact translated and originally written in Germany by

a German, Erich Maria Remarque – All Quiet On The Western Front. Erich Maria Remarque, wasn't a member of the officer class. He was a private on the western front. In fact literati like George Orwell were caustic about his book. But first published in 1928, ten years after the war ended, it was probably the most powerful and influential text from the war. As Kelly who wrote definitively about the filming of the book said, it was:

a bombshell. Of the hundreds of books published about the war it was the one read most widely, and the one most influential in laying the foundations for a new view of the war as brutal, pointless waste. The impact of this should not be underestimated; during the war propaganda was one-way, and even those who had fought at the front had been reluctant to let their loved ones hear the truth.

Remarque said that he was writing about direct experience. 'The details of my book are real experiences', he protested, when the Nazis tried to spread rumours that he had never served on the front line and that the conditions and attitudes he depicted were not true. (Tims, 2003, p57) In his dedication Remarque wrote:

This book is intended neither as an accusation nor as a confession, but simply as an attempt to give an account of a generation that was destroyed by the war – even those of it who survived the shelling. (Remarque, 1996, Dedication).

A recurring theme for Remarque was the relation between war and knowledge and the significance of first hand knowledge. The point made by Remarque and the book's characters was how important their experiential knowledge was and how irrelevant the knowledge with which they were equipped for the lives they were set on. What was important about this point when Remarque made it, was that it was an exact reversal of conventional values and assumptions. Traditionally we have had the histories of kings, emperors, generals and field marshals. It is still what we get. Education Minister Gove now wants to take us even further back to it. It was Remarque's goal to challenge this and offer young people's own history.

Remarque's *All Quiet* emphasises the essentially political nature of personal accounts. It's power is not only to be measured by the influence it has had on the rest of us and our understandings of war in the years since. It can also be judged by the responses of its enemies, notably the Nazis. They seemed to prefer books like Ernst Junger's *Storm Of Steel*. (Junger, 2003), depictions of the western front full of blood action and heroism.

All Quiet had some disasterous effects for key people close to it. Remarque paid a high price for trying to tell truths about his generation. He was hounded by the Nazis, who burned the book. He was stripped of his citizenship and exiled from Germany. During the war, unable to reach him in America, the Nazis took revenge on his favourite sister, Elfriede. She was charged with 'defeatist talk' and 'subversion of military strength' and beheaded by guillotining in 1943.

(Tims, 2003) Lew Ayres, the American actor who played the hero of All Quiet in the film became a pacifist as a result of his involvement in it. He was a conscientious objector in the second world war and as a result his Hollywood career was blighted. (Kelly, 1998)

My point is that All Quiet and the Great War are far from isolated incidents in this discussion. Right up to the present, through the Second World War, Vietnam and Iraq, through to Afghanistan, there are constant first hand accounts of war. The answer is perhaps because so far war has provided the most ready market for such 'grassroots' first hand accounts. It offers unique access for the ordinary person. It represents an extreme case where world events intersect with human biography. There are few if any areas of human activity where so much has been written by so many 'ordinary people' about their own experience. Few such accounts are as powerful as Remarque's however. It is very difficult for such accounts to have an impact and that usually is only retrospective – when the damage has already been done. Second, as Kelly suggests, such accounts can be difficult to hear and those who have been through the experience are often reluctant to communicate it. A common theme amongst those with experience of war, is their reluctance or inability to talk about their experience to others who don't share it, including even those very close to them.

It is the preoccupation with experiential knowledge of works like All Quiet onwards that is why it is pertinent to this discussion. Here then

is the connection between it, the kind of research that I do and our focus today.

If war is one of the most cataclysmic and all-embracing experiences that human beings can become embroiled in, then being a mental health service user is an identity over which people included in it seem to have had remarkably little control. Mental health service users are circumscribed by a diagnostic system of definition, which conceptualises them in increasingly narrow medicalised terms. This provides the basis not only for how they are understood and perceived, but also for the responses that are made to them, the formulation of knowledge about them and frequently how they see themselves. We have just seen the publication of DSM5, the latest version of international psychiatric diagnostic definition. Thus mental health research is particularly medicalised in its approach, largely based on the dominant diagnostic system; preoccupied with the testing of biochemical responses to people and largely committed to positivist approaches to research where traditional quantitative research methodologies of randomized controlled trials and systematic reviews continue to be seen as the gold standard for knowledge creation.

Mental health service users' own direct experience and their interpretations and understandings of it have largely been ignored, devalued or marginalized. Their experiential knowledge; that is to say the knowledge that has grown out of their experience, emotions and perceptions, has historically been seen as having little value. Given

that their defining characteristic is seen to be their unreason; their irrationality and morbid unpredictability, threat and potential danger, this might be expected.

What we are beginning to see now, however, as mental health service users have developed their own discussions, organisations, movement and collective action in recent years, is that their views of themselves and the world are wildly discrepant from the medicalised ones that have predominated. Thus, many mental health service users see the medical model on which basis they have been understood, as damaging, stigmatizing and unhelpful. They report the unreliability and inadequacies of the diagnostic system they have been subjected to and the limitations and partiality of the consequent predominantly drug-based responses to them, highlighting their limitations, damaging effects and the over-reliance that has been placed on them. They argue instead for more holistic, social approaches to understanding them and their situation and to responding to them. As they have over the last 20 to 30 years begun to engage in research and develop their own survivor research, they have also emphasized the importance of their direct experience both in the undertaking of research and in the generation of new and helpful knowledge.

I believe that there are some helpful lessons to draw from this – these are what I would suggest:

People's own direct experience and the knowledge they can form from it are crucial for all our understanding. However, a growing range of what seem increasingly powerful mediators get between people and their experience, alienating them from it and often working to alienate others from them. These mediators range from the media to traditional researchers; from the 'helping professions' to the political process and prevailing ideologies. We seem under the present UK government to be living at a time when politicians seem particularly committed to creating and reinforcing divisions in society. We are encouraged to hate others and perhaps to hate ourselves. Thus the negative emphasis on immigrants, people on benefits, disabled people, mental health service users, baby boomers getting more out of the welfare state, people with public sector pensions, travellers, teenage mothers and so on and so on.

People coming together with shared experience with opportunities for reflection and reflexivity can challenge prevailing understandings. Groupings and organisations which people themselves control, like user led and disabled people's organisations, are just such examples of this and have provided the home for the development of different ways of understanding, responding to and researching with people.

We do, as the disabled people's movement first highlighted nearly a generation ago need to develop research based knowledge that rests on more inclusive and egalitarian principles; research that is committed:

- To equalizing the relationship between researchers and researched
- Which values the subjective and, questions positivist research values
- Which values direct experience in both researchers and researched and gives priority to the development of experiential knowledge
- Which sees as its goal the empowerment of research participants and the making of broader social and political change in line with this, rather than just the accumulation of knowledge for its own sake.

Such an approach to research and indeed to social action makes it possible for people to be an equal part of the process, rather than foot soldiers enlisted and directed by a self appointed vanguard. I would argue that this is not only important for challenging the present dominance of neo-liberal and individualised ideology and action, but without its advancement, such a broadbased challenge is unlikely to emerge that is likely to be effective or successful.

This emphasis on experiential knowledge makes it possible to challenge the orthodoxy of positivist research and assumptions about knowledge development. It calls into question its crude scientism that is essentially reductionist and allows us instead to engage with the richness of human experience and understanding without devaluing or belittling either.

It means that instead of accepting simplistic positivist assumptions about the importance of neutrality, distance and objectivity in research, we can begin to be honest that such principles may actually themselves be unreliable and fallacious. That is why I have raised the hypothesis which I believe user controlled/survivor research leads us to consider that instead of emphasizing separation between research, the researcher and the researched:

The *shorter* the distance there is between direct experience and its interpretation (as for example can be offered by user involvement in research and particularly user controlled research), then the *less* distorted, inaccurate and damaging resulting knowledge is likely to be. Thus as Pettican has said (2013, p9), this concern with democracy and the devolution of power in terms of knowledge generation is a defining feature of service user/survivor led research. That I believe must be our goal here too.

If we are to take this forward we must be clear about our principles. We must build, groupings, alliances and solidarity for taking it forward. We must challenge the isolation that many mental health service users and others face which restricts their potential to participate in such ventures and perpetuates their disempowerment. We must search for our shared experiences, values and goals rather than retreat to segregated identities.

Just as there are enormous opportunities for more participative research providing the basis for the development of more inclusive experiential knowledge, so there are major threats and barriers. We have to challenge these and break through the crude walls between researchers and service users, between learners and educators, between professionals and service users, which don't reflect the reality of our multi-faceted identities and our complex diversity. There also need to be new and reinforced alliances between different professions and educators in different fields; between practitioners, professional organisations, local trade unions, carers organisations and disabled people's and user led organisations. I feel that organisations like SWAN the Social Work Action Network already reflect these values, commitments and ways of working. We have a chance for something truly different here. We have the chance to develop together knowledge bases that can strike back democratically at the increasing inequality, want, discrimination, exploitation and exclusion that are being strengthened as routine characteristics of our and other societies. In so doing, we will resee ourselves and our potential, helpfully reconceive research, add to our knowledge base and move to more inclusive of living and understanding. Thank you.

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