

Peter Beresford

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**Part 3: How We Have Got To Where We are – And where we
might be going**

Hello everyone, it is good to be here today and a privilege to be asked to make this contribution.

I think an underlying theme in what I want to talk about today is the importance of unification or reunification; reconnecting at every level, from the personal, through policy to the political, if ideas and practices of user involvement and public participation are to be meaningful, have an impact and to make serious inroads into the nature of the worlds we inhabit.

Let me briefly explain why I have come to this conclusion and then take you through what I see as some key stages in the development of public participation in modern times and also some of the key problems that I believe have encouraged the impetus for such involvement, as well some of the key concerns it must engage with if it is to challenge these problems. Also, if I have time, I would like to try and signal how problematic participation tends itself to embody those same problems rather than to displace them. That is to say the

irony that some participation actually reflects rather than challenges the exclusions and barriers that we may imagine it offers a remedy to. Participation thus is not necessarily on our side – depending of course on who ‘we’ are!

So let me briefly describe what has led me to this viewpoint. This is the fortieth anniversary year of work that Suzy Croft and I have done engaging in issues of participation. We, I - have done this in different policy areas, in different areas of participatory activity; where pressure for participation has been underpinned by different ideological motivations. We have done it from different perspectives, as worker and activist, educator and practitioner, researcher and commentator. I have done it from different settings, from community groups and organisations, from user led organisations, from large formal policy and charitable organisations, from research and educational organisations. So in one sense. this is a very personal critique, but it is one that has engaged with and drawn on the work of very many others, locally, nationally and internationally, as researchers, activists, educators, policymakers and practitioners, but mostly as service users and other engaged citizens.

By way of introduction let me say that I believe we seem to be at a significant stage in the development of such citizen participation. And this is our opportunity. But first I need to sketch out what I would identify as four key phases in modern interest in and pressure towards greater public participation getting us to this point. I see

these as international in their scope. I can only headline them here but I can refer you to a more detailed discussion of them. Also I think such an historical perspective can offer us much more in making sense of and taking forward participation than more conventional reliance on models and typologies.

Phase 1, I would describe as working for universal suffrage and social rights. The first half of the twentieth century was a particular time of increasing democratization of representative political structures and the extension of suffrage in the UK and beyond. But this time of increasing international political, economic and social conflict uncertainty and inequality, rising pressure for electoral representation also came to be coupled internationally with pressure for the achievement of social rights. Such rights are taken to include the right to work, to decent housing, education, adequate income and social security and proper social, health and medical services and the achievement of these rights was associated with the creation of post second world war welfare states.

Phase 2 can be summed up as the development of provisions for participatory democracy and community development, and is associated with the 1960s onwards and can be seen as a reaction to the paternalism and top-down nature of post-war welfare states which were at least non-participatory if not actively anti-participatory. Legislative requirements for participation for example in land planning and schemes for community development emerged to counter the continuing problems of poverty, exclusion and inequality that had not

been resolved by the expansion of state welfare.

I would headline Phase 3 as Provisions for participation in health and social care (although they can be seen as broader than this) developing from the 1980s – this is the phase of development that generally tends to be seen as the starting point for considerations of user, patient and public involvement. It is coupled with two major developments; the emergence of user movements committed to challenging the exclusion and marginalization that they saw themselves as experiencing and, broader shifts to the right in political ideology associated with neoliberalism and the New Right, committed to consumerism and the market and the diminution of state intervention and involvement.

Finally, where we are today, Phase 4, perhaps best described as Reaction and Renewal, where the tensions between competing ideological underpinnings and objectives for user and public involvement have become more manifest, with the service system as much subverting service users' aspirations for say, empowerment and involvement as supporting them, coupling rhetoric about engagement with welfare reform policies of impoverishment and exclusion; and service users and their organisations increasingly recognizing this, appreciating the continuing discriminations, inequalities and exclusions they face and beginning to articulate more independently their own ideas, agendas and campaigns for say and involvement.

If anything should give us pause for thought about participation it is being where we are today in its history. If anything should highlight its ambiguity and potentially regressive implications, it is the way statutory initiatives can now be seen to be co-opting key concerns of service users like self-management, peer support, recovery and personalization, putting them to reactionary purposes.

This brings me to the second part of my discussion. There are identifying criteria to judge all this by. For all the talk about PPI, user involvement, public participation and the ways in which they have crept into the political and policy lexicon, I want to highlight a series of continuing obstacles in the way of them being meaningful and effective, which can make up the context for their operation and potential. These are all issues that connect with problems of separation and inequality which I touched on in my introduction. These apply between us, for example,

- As service workers and service users; in contexts that are increasingly disempowering for both;
- As practitioners/field workers and managers in increasingly hierarchical controlling structures;
- As service users and family carers where too often one is put in the position of speaking for the other and the needs of the two are conflated and confused;
- As public and service users, as if the latter aren't part of the public and should be conceived as a negative cost on the former, with insidious propaganda about the scrounging and

- dependence of disabled people and other groups of service users;
- Between so-called 'expert' or professional knowledge, research based knowledge and the lived experience of people as service users, with the latter devalued as biased, unscientific, subjective and unreliable and user controlled research which gives value to it, similarly devalued in relation to traditional valuing of conventional randomized controlled trials and systematic reviews.
 - Between us - on the basis of issues of diversity in relation to age, gender, ethnicity, sexuality, disability, class, culture and belief, so that some groups face discrimination in society and frequently schemes for participation mirror these.

The long term trend in public policy has been to reinforce these divisions, inequalities and exclusions. While the post-war UK welfare state increasingly struggled to overcome its initial inequalities, the tendency of later and current neoliberal policy and politics has instead been to reinforce them, with its modern rhetoric dividing us into 'scroungers' and 'strivers'; employed and unemployed, 'hard working' and 'troubled families', citizens and non-citizens; 'dependent' and 'independent'.

How then do we challenge this, if our understanding of participation and involvement is one concerned with challenging regressive power inequalities; supporting empowerment, rather than marketization, commodification, and ultimately disempowerment; if we are

committed to anti-discrimination rather than discrimination?

To make sense of this, let's start with those seeking their own participation and inclusion and in my view the right place to do this is with the self-organisation, the user led organisations established by disabled people and service users organisations from the 1970s. Here some of the most marginalized and disempowered groups; people with physical and sensory impairments, people with learning difficulties, mental health service users and others with long term health conditions, took the initiative and began to speak and act for themselves; struggling for self-advocacy and self-organisation. As their early organisations spelled out, their goal was inclusion, integration on equal terms and participation in society, rather than segregation and marginalization. They had experienced separation and inequality. What they wanted was access to and inclusion in the mainstream and to be treated on equal terms. To achieve this, groups like disabled people emphasized their separateness; they were often separatist in their approach, but their aim was to put an end to the discrimination they understood disability to mean and to achieve inclusion, unification and reconciliation. The strategy was inclusive, aiming for unity and the equal recognition of difference; the tactics were often separatist on the basis of difference. By highlighting their difference, they sought to be treated with equality and achieve unity and inclusion.

Increasingly while recognizing their difference, as for example, disabled people or mental health service users, they highlighted their

internal diversity and their overlaps with other groups. They highlighted that even within oppressed and marginalized groups external hierarchies around gender, ethnicity, sexuality, age, impairment and so on, could operate and they increasingly evidenced and challenged the way that such exclusions operate to mean that some people within such groups face discrimination, face particular discrimination, for example disabled women and Black disabled people. They analysed these oppressions through the lense of intersectionality and began to challenge them, themselves. They also began to evidence the many groups who tend to be marginalized and excluded even by participatory initiatives; for example, people who communicate differently, who live in institutions or are homeless, or are seen as 'too impaired' to be involved, disruptive or challenging.

They have revalued lived experience and the experiential or first person knowledge that grows out of it and argued that it should be treated as having equality with other forms of 'expert', professional, or research knowledge. They revalidated such first person knowledge not only in relation to service users and their experience, but also with regard to health and welfare workers and the 'practice wisdom' that grows from their work experience, encouraging an understanding of their 'knowledge' that is not narrowly restricted to what they as workers are taught on formal professional courses, but which also takes account of and draws on their own experience through their roles and identity; the oppression, life and identity issues that they face. They challenged narrow understandings of what counts for knowledge and traditional inequalities surrounding knowledge claims

and so-called epistemic injustice, where some are seen as more credible knowers than others. This is divisive and also damaging to those who face the kinds of problems that results in them becoming the subjects of traditional social research.

They have called into question the values of distance, neutrality and objectivity of conventional mainstream positivist research and instead highlighted that these devalue their lived or subjective experience and represent a further layer of discrimination imposed upon them, invalidating their understandings of the world. They developed instead an emancipatory disability, survivor or user controlled research which prioritizes equal relationships in research as well as personal empowerment and social and political change as its objectives. They question the independence of mainstream/conventional research which is frequently tied to government priorities and ideology for funding and is often tied to the values and assumptions of the service system.

I want now very briefly to end with two developments which characterize current efforts of service users and their organisations and allies to develop their own user led alternatives to dominant participatory discourses and developments. These are PowerUs and Mad Studies, both of which I am actively involved in. Both can be seen as counters to the negative potential of participatory initiatives outlined here as well as embodied features of current user-led challenges to it. Both seek to be inclusive of people from different standpoints but with a genuine commitment to emancipatory

participation; both recognize problems in relation to ensuring diversity and seek to address them; both reject traditional elitist/exclusionary approaches to social and welfare policy and both are now gaining international significance.

First is gap-mending, pioneered by the European alliance of professional educators and service users, PowerUs. Involving service users (and family carers) in professional education and training has long been seen as one of the most effective ways of improving the nature and culture of social work. PowerUs, a partnership of social work educators and service users which already involves twelve countries, has sought to develop methods of mutual learning in order to change social work practice to be more effective in supporting the empowerment of marginalized groups (<http://powerus.eu>). Its 'gap-mending' process first initiated at Lund University Sweden, brings service users and social work students together to learn together on as equal terms as possible. The idea is about bridging divisions between service users and social work students in their learning through new approaches to user involvement. It also represents an alternative approach to the increasing emphasis under neoliberal politics on graduate and elite/fast track approaches to social work education, giving value to 'user knowledge', rather than just academic qualifications. People 'meet as people' on gap-mending courses; service users get formal recognition and accreditation for the skills they offer as well as the skills they gain. Social work students with 'lived experience' as service users are valued for it and can share it if they wish to. Perhaps most important is the building of trust and

understanding between service users and would-be social workers which is likely to have a profound effect on future relations and practice between them

Second is Mad Studies. The 'Mad Studies' movement is committed to a praxis for radical change and is strongly rooted in Canada and also increasingly in the UK and internationally. For me this has become perhaps the most important development that has grown out of a search for new understandings of distress which places value on the lived experience and knowledge of mental health service users.

'Mad' continues to be a contentious word, not surprising given the abusive, pejorative and devaluing way it has long been used. I think it has been deliberately revisited by Mad Studies to show a determination to reclaim the word by those who identify as service users, as experiencing distress, and their allies. I feel Mad Studies offers real hope for the future. It is exciting because of its potential to bring about positive change.

I think the rise of right wing politics, combined with the increasingly assertive expansion of the psychiatric system have worked to stifle alternative ways of understanding and responding to distress. They have formed a powerful informal alliance that focuses on the individual, their responsibility so seen for their problems and the assumption of things wrong in our heads.

I believe Mad Studies has an unprecedented and unparalleled potential to challenge this status quo which I believe is unhelpful and damaging. It offers a real possibility to move on from a narrow medicalised individualising model; that is closely tied to racialising distress and which is particularly damaging for indigenous populations and others facing structural discrimination. It links us up in our different roles and standpoints; to give equal priority to user knowledges and experience taking us beyond over-reliance in professional and medical authority and expertise.

Nobody owns Mad Studies we may all understand it in different ways, but for me what is critical about it, what defines the key elements of mad studies is that:

First, it is definitely divorcing us and itself from a simplistic biomedical model – It allows other understandings and disciplines to come into it instead of solely medical dominance – sociology, anthropology, social work, cultural studies, queer studies, disability studies, history, everything

Second is the value and emphasis it places on first person knowledge – centring on the first person knowledge of everyone, not just those psychiatrised. If you want to talk about yourself, then you have a right to, it is ok to include yourself (this is positioned/situated research – you can't be talking from nowhere, as if you had no place in the proceedings – as it has been in psychiatry)

And of course Mad Studies treats survivors' first hand knowledge with equality. But Mad Studies values and has a place for all our first hand experiential knowledge; that's why such a wide range of roles and standpoints can contribute equally to Mad Studies if they are happy to sign up to its core principles. It isn't only us as survivors/mental health service users, but allies, professionals, researchers, loved ones, etc etc, this is a venture we can all work for together in alliance.

So it includes the experiential knowledge of service users, the practice knowledge/wisdom of workers and the knowledge from those offering support, of family carers as important bases for future mental health policy. I think this is important because all three still too often can get left out.

I must stop here, I have tried to offer a critique of how and where we have got to in public participation and user involvement that is connected to the broader ideological, political and democratic issues that it is truly inseparable from. I have also Identified conditions associated with the denial of such participation as well as key examples of how it is being taken forward.

- Starting with our separation we seek to create unities;
- We work for unification, anti-discrimination and reconciliation;
- We seek to address diversity with equality;
- We value the inclusion of all ourselves – all our experience, all our identities;

- We own and value all of ourselves and all our knowledge
- We support research which treats all our knowledge with equality; first hand as well as so-called 'expert'.

Critically participation must embrace the personal and the political and their interrelations; personal empowerment and the capacity to make wider change collectively. It must be concerned with these two related aspects of change. I hope the issues I have raised today can be part of a growing and inclusive discussion about participation that will offer more hope for the coming 40 years than for the 40 years I have experienced and build more determinedly on the efforts and commitment of the people from different standpoints and identities who have got us to where we are now.

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