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Public Participation in Health and Social Care: Exploring the Co-production of Knowledge

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Efforts to advance public participation in health and other policies have been associated with the production of many models and how-to-do-it guides for change. While these may have a helpful part to play in improving public and patient/user involvement in research, in this article it will be suggested that they tend to over-simplify things. Instead it is argued that an essential first step to advancing public participation in health is to put it in the context of developing modern democracy more generally. This article will seek to do this by identifying four key stages in the development of public participation in health and social care. These phases will be headlined as:

- Working for universal suffrage in representative democracy and the achievement of social rights, like the right to decent housing, education and health;

- Provisions for participatory democracy and community development;

- Specific provisions for participation in health and social care;

- State reaction and service user-led renewal as conflicts and competing agendas develop.

While the proposed article will look particularly at UK developments to do this, it will also draw upon international experience and highlight the wider relevance of these phases of development. It will make connections between the extension of representative and participatory democracy, considering the different locations in which efforts to extend participation have helpfully developed, for example, in learning and training, and research and knowledge production. It will also consider how efforts to extend participation have also been undermined by pressures to tokenise and co-opt them; the continuing barriers discriminating against some groups and, ways in which service users and allies have nonetheless sought to overcome these difficulties to take forward more inclusive and diverse participation in health and social care. It will focus on some particularly promising areas of development internationally in order to do this in which co-production and the development of user-led knowledge are key.

Introduction

There can be little doubt that there is currently significant and widespread interest in public and patient involvement in health and social care services, policy and research. This special issue of the

Journal is just one more token of that. But interest should not be confused with progress or consensus. This situation is compounded by inequalities and competing interests between key stakeholders in the venture; between government, its research institutions, researchers and family carers, service users and our/their organizations and movements. There has been a surprising lack of progress in the development of such public and patient involvement in health and social care and a tendency to isolate the issue from its broader relations, for example, institutionalizing it as separate entity and abstracting it from its ideological connections. It has even been turned into an acronym in the UK-PPI–for public and patient involvement (Moini, 2011).

There are some noticeable features about the way the dominant discussion about such PPI or public and service user participation in health and social care has developed over the years. First, it has mainly come from people with interest and expertise primarily in health rather than in political participation. A measure of this is that publications tend to be located in health and social policy journals and other publications, rather than politics or political theory ones. For example, an international peer reviewed journal concerned specifically with participation was initiated in 2014, but while being multi-disciplinary, it situates itself specifically in "health and social care" and its title, *Research, Involvement and Engagement* (https://researchinvolvement.biomedcentral.com) offers a clue to its narrowly technicist and research-based focus.

Where an interest has been shown in political processes, it has tended to be limited to so-called deliberative or discursive processes, in which there has been specific and growing interest. Here bodies like citizens' juries and local committees are set up to discuss and vote on policies and budget allocations. While the pressure for deliberative democracy can be seen as expressing a will for something beyond representative democracy, it also seems to be tied to many of the limitations associated with the latter.

The sociologist and political philosopher Anthony Giddens drew an early distinction between traditional liberal (representative) democracy and deliberative democracy.

Liberal democracy is a set of representative institutions, guided by certain values; deliberative democracy is a way of getting, or trying to get, agreement about policies in the political arena…The important thing is that the participants reach a judgement on the basis of what they have heard and said (Giddens, 1994, p. 113).

Giddens didn't see such deliberative democracy as necessarily participatory—"it is not defined by whether or not everyone participates in it"—although its advocates have tended to present it in that way. For him its distinguishing mark is that wider publics are able to discuss and come to their own conclusions about policies and politics. Thus, he sees democratization "as the (actual and potential) extension of dialogic democracy…where such communication forms a dialogue by means of which policies and activities are shaped" (Giddens, op cit, pp. 114–115). This might work well on the academic page, but it is difficult to make it happen in the real world where things are less neatly compartmentalized.

Conversations and debates do not happen in isolation and people bring to such discussions all the influences they have been subject to and their own socialization.

Such deliberative structures and processes tend to reflect prevailing values and opinions, often gaining a life of their own which may not reflect wider views and frequently face difficulty in reflecting the full diversity of the communities for which they speak. They tend instead to reflect broader inequalities of status and power so that the voices of white middle class males still often predominate–as in mainstream political processes. They are also constrained by another dilemma and paradox. They tend to be initiated by the very local or central state which is the product of the ruling system and which ultimately determines what if any notice is taken of them. Such deliberative structures can be seen as the ultimate talking shop, often overlaid with a reactionary edge (Dolan et al., 1999; Fishkin and Laslett, 2003; Williams, 2004; Davies et al., 2006; Fishkin, 2011).

Second, debate on participation in health has been strongly influenced by the political agendas of politicians, policymakers and professionals, reflecting prevailing imbalances of power and ideology. Thus, PPI has been appropriated as an evaluation measure in the consumerist UK universities Research Excellence Framework (REF, formerly Research Assessment Exercise or RAE) and in government research funding allocation processes. It is also judged by an economistic understanding of "impact" through which an increasing political emphasis has been placed, although of course the concept can be a much more far-reaching one (Staley, 2009; Cotterell et al., 2011). Third, it has been characterized by a particular interest in models, typologies and practical "how to do it" guides for involvement.

One of the earliest and still one of the most often cited and discussed of these, is Arnstein's "Ladder of Citizen Participation" (Arnstein, 1969) The problem with such uni-dimensional approaches to participation is that while in some cases recognizing power differences, they still struggle to address its essentially *political* nature. While they can have a helpful part to play in improving public and patient/user involvement and understanding of it, they also tend to be reductionist, over-simplifying and ill-suited to dealing with the real life complexities and ambiguities of such involvement (Beresford and Croft, 1993; Wilcox, 1994; Tritter and McCallum, 2006). All these pressures have had the effect of isolating participation from its ideological and political relations–particularly its relations with ideas, theories and practices of democracy and democratization.

In this it reflects social or public policy more generally, where the tendency has long been for them to be treated as neutral technical matters. This gave rise to the discipline of social administration and a "social administrative" model for understanding and analyzing public policy. This was typified by Fabian social policy where the political was underplayed and policymaking presented much more as a matter of neutral technical expertise, best left to academic and other "experts." It was service users' exclusion from this process, their consequent revulsion from it and the political right's populist attack on it that overlaid western social policy in the last quarter of the twentieth century and underpinned the emergence of conflicted understandings of public and service user involvement in health and social care (Beresford, 2016).

A Different Approach

My own journey to an interest in public participation and user involvement has been a different one and perhaps this helps explains why the route I have taken has been different too. My engagement with the issue has been a long one–now totaling over 40 years. It has also been multi-facetted and extended across different roles (including as a service user, and advocate and as a "local person"); different policy areas and forms of participation underpinned by different ideological motivations. I have been involved as academic, educator, researcher, activist and service user; individually and collectively, in grassroots organizations, as well as policy and practice ones, in bottom-up community-based and user-led initiatives and large charitable and policy organizations, as well as local and central government and international initiatives and committees. I have been very fortunate—and unusual—to connect with participation over such a long period and from such a wide range of perspectives and settings. 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.

However, it is also important to highlight that there are particular barriers in the way of service users and their organizations networking and developing their own knowledge locally, nationally and particularly internationally (Branfield et al., 2006). User led organizations face particular barriers accessing funding related to the discrimination they face. Their international organizations face especial difficulties exchanging knowledge and experience because of the costs of travel and support involved (Shaping Our Lives, 2018). This author is not exempt from these problems and this imposes limits in the way of fully internationalizing accounts and studies. Mainstream non-user academics and researchers are much better placed to operate internationally. This can be seen as another expression of the epistemic inequality and injustice that has been increasingly identified as operating between conventional researchers and groups facing discrimination, marginalizing their experiential knowledge and devaluing them as “knowers” and producers of knowledge (Fricker, 2007; Liegghio, 2013, p. 124; Russo and Beresford, 2015). And yet despite the very real obstacles in their way, service users have nonetheless managed both to accumulate and share international experience and to influence major supranational bodies, like the United Nations (O'Hagan, 1993; Minkowitz, 2018).

My background has particularly encouraged me to adopt an historical perspective and highlighted its benefits in trying to understand participation. There seem to be few such discussions of public participation. Perhaps this is because it cuts across so many different disciplines, policies and professions and demands an overview and level of familiarity with these not readily gained. Furthermore, building on wider experience, a premise adopted here is that to make sense of participation in health, it is likely to be helpful to look beyond health and to take the development of participation as a starting point. Thus, here it is suggested that an essential first step to advancing public participation in health and the advancement and co-production of knowledge within it, is to put it in the context of developing modern democracy more generally. Here it is argued that when we try to do this, four key stages in the development of public participation in health and social care can be identified. These historical phases are associated with:

1. Moves toward universal suffrage in representative democracy and the achievement of social rights, like the right to decent housing, education and health;

2. Provisions for participatory democracy and community development;

3. Specific provisions for participation in health and social care;

4. State *reaction* and service user-led *renewal* as conflicts and competing agendas develop.

These phases shouldn't be seen as narrowly sequential. Overlaps and inconsistencies can be identified. They highlight the need not to isolate or reify developments in participation. These have taken place in different ways, at different times and paces in different situations and countries. They may also interact and co-exist with each other in different ways. But the broad phases identified here do nonetheless, seem to reflect wider international political, policy and ideological trends.

While this article focuses particularly on UK developments to explore this history, it also draws on international experience and highlights the wider relevance of these phases of development. It makes connections between the extension of representative and participatory democracy, considering the different locations in which efforts to extend participation have helpfully developed, for example, in learning and training, and notably in research and knowledge production. It also considers how efforts to extend participation have been undermined by pressures to tokenise and co-opt them; the continuing barriers discriminating against some groups and, ways in which service users and allies have nonetheless sought to overcome these difficulties to take forward more inclusive and diverse participation in health and social care. It will focus on some particularly promising areas of development internationally in order to do this in which co-production and the development of user-led knowledge are key.

Phase One: Moves TOWARD Universal Suffrage and Social Rights

Looking back from our vantage point in the early twenty first century, it can still be alarming to be reminded how long it took to achieve universal suffrage even in supposedly “advanced western democratic societies.” Thus, it was not until 1918 in the UK that the Representation of the People Act gave women the vote provided they were aged over 30 and either they, or their husband, met a property qualification. Until 1918, when the property qualification for men was abolished, only about 60 per cent of men had the vote. The rate of change was rapid. In 1900, <7 million people in the UK had the right to vote. This had risen to more than 21 million, more than half the population by 1918. However, not until 1928 under the Equal Franchise Act did women in the UK share equal voting rights with men (Smith, 2014). Most European countries adopted highly discriminatory suffrage systems for lower legislative chambers for most of the 1815–1915 period (Goldstein, 1983). In many places Black people have only obtained suffrage through national independence during the course of the twentieth century and in some countries it continues to be an issue even where it has been formally achieved (Paxton et al., 2003). Indigenous peoples also continue to face discrimination and marginalization globally (Anaya, 2004).

However, if the first half of the twentieth century was a time of increasing democratization and the extension of suffrage, it was also a time of growing suffering worldwide. The two world war and international inter-war economic depressions, caused enormous problems of want, death, disease, suffering and hunger globally. More people died in the Spanish flu epidemic after the Great War than were killed in the war itself (between 20 and 50 million). In a time of increasing political, economic and social uncertainty and inequality, rising pressure for electoral representation 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 (Beresford, 2016).

This first major expression of the struggle for “social citizenship” was the setting up of post-second world war welfare states, first in the UK and then other countries. One of the central policies established as part of the UK welfare state was the National Health Service (NHS), based on principles of providing universal health care free at the point of delivery and paid for out of a progressive system of general taxation The UK welfare state's proponents saw it as having a key role to play in the protection and promotion of people's economic and social well-being. The welfare state's policy provisions and legislation were seen as compensating for inequalities arising from the market, in contrast to the Poor Law which sought to police and regulate people disadvantaged in society and through the market (Marshall, 1950). What such thinking failed to take account of, as subsequent critiques from feminist, LGBTQ, Black and disability rights perspectives have highlighted, were the inherent biases of such concepts of citizenship which were very much tied to the thinking and discriminations of their time (Williams, 1989; Oliver and Barnes, 1998).

Phase Two: Provisions for Participatory Democracy and Community Development

The initial struggle for political and social rights can be seen as leading to the second stage of struggle for greater democratization. If the first phase was concerned with extending representative democracy, this second phase can also be seen as influenced by ideas of participatory democracy. It is concerned with ways in which people can be involved directly in the political process, rather than being represented by others and can trace its history back to the origins of democracy in ancient Athens, where all who counted as citizens could thus participate–although the lines of citizenship were drawn very narrowly (Held, 1996).

In the UK, the beginning of this second phase of interest in participation is associated with the 1960s and was linked with the return to power of left of center Labor governments after years of right of center Conservative government. There were equivalents both in other European countries, the United States and beyond. Talk in the UK was framed in terms of the “rediscovery of poverty” in the midst of what was seen as an “affluent society” This discovery was associated with major social science academics like Peter Townsend and Brian Abel-Smith, who combined research with activism (Abel-Smith and Townsend, 1965). Post-war “consensus” between political left and right, that mixed economy welfare states had secured the rights and social security of citizens “from cradle to grave” was challenged. The social policy theoretician Titmuss and others pointed out that welfare services established to counter-balance inequalities in society were failing to do so and that longstanding inequalities and exclusions remained (Titmuss, 1968; Halsey, 1972). Public and social services were emerging as having their own problems and limitations as an approach to compensating for structural problems and inequalities.

As rising inequalities, exclusions and regressive redistribution were highlighted in the UK and internationally, a range of focuses and approaches for change were developed. These centered on concepts of social compensation, urban interventions and community involvement. Community based approaches range from highly structured, state and professionally-led schemes operating in localities and around issues, to much more autonomous approaches encouraging independent collective action in the community, developing ideas of “empowerment” and “conscientization.” All highlight participation, but there has been a tendency in both toward increasing professionalization and state control (Craig et al., 2011; Ledwith, 2016).

Thus, the US "War On Poverty" (Sheffield and Rector, 2014) and in the UK the state-led community development project (CDP), which ran from the 1960s to late 1970s and the education priorities areas (EPA). Both sought to target help on particular individuals and groups (including women, young people, Black and minority ethnic groups and poor people) and areas (notably "inner city areas") identified as deprived and disadvantaged. All sought to "involve" the people they were working with, although they were generally professionally led. They aimed to raise people's consciousness, skills and "cultural capital." All placed an emphasis on support, out-reach and developmental work, to help make this possible. But all equally came under attack for their ambiguity. Competing strands were identified in the work, some more consensual and some conflict based (CDP, 1977; Loney, 1983). Local involvement was often limited, tokenistic and paternalistic. Poverty remained a continuing problem and was indisputably linked with persistent (and ultimately worsening) economic and social inequality in British society and institutions (Atkinson, 1983).

If involving people was part and parcel of the UK community development and anti-poverty strategies of this time, it was the central feature of new provisions for state land planning. This movement gained momentum in the late 1960s not least because of the deluge of bad planning with large scale urban redevelopment and, central government's desire to free itself of the burden of innumerable appeals. Its landmarks were a major government report and two town and country planning acts of 1968 and 1971 (Beresford and Beresford, 1984, p. 27). For the first time, the legislation made provision for public participation in planning–both development planning and general planning control. This became a model that attracted international interest. The notion of public participation embodied in the two acts was essentially one of public consultation and appeal. The "public" was offered the limited chance to disagree with what the local authority offered. Not only was participation limited to reacting to existing plans and proposals, rather than being able to co-create these, but the involvement engendered, tended to be very limited.

One of the abiding problems of modern public participation, as we shall explore later, has been the barriers and restrictions that seem to operate on who actually gets involved. This has been an issue that has been associated with all efforts to involve people. It was rapidly apparent in efforts to involve people in land use planning. These exercises, essentially based on expecting people to respond to invitations to get involved and relying on traditional public meetings and conventional verbal and written skills, tend to disadvantage and exclude people on the basis of class, ethnicity, gender, age, culture and disability (Beresford and Beresford, 1984). They also tend to put a premium on verbal, writing and other social skills, which inherently discriminates against less confident, less assertive, less well educated people. Thus, they may actually reinforce inequalities in relation to power and participation, rather than compensate for them.

They also exhibit another major shortcoming, which again is not confined to statutory arrangements for participation in planning. As one commentator, campaigning against redevelopment where he lived, observed early in their development:

> Millfield benefitted greatly from the termination of public participation in planning…In Millfield…specific issues connected with the planners' proposals were brought to a moderately successful conclusion (from the residents' point of

view) only when the planners' rules were abandoned and the ordinary machinery of local councilor, MP, publicity, public discussion and so forth was utilized (Dennis, 1972).

This is an inheritance which participatory initiatives still have to live down. While ostensibly intended to extend democracy, they can actually serve to divert people from the long fought-for provisions for representative democracy, offering no more than a tokenistic dead-end that discourages people from pursuing what may actually be more firmly established and effective structures for representative democracy. This is a much broader issue for arrangements for participation. Both community development approaches and provisions for participation in planning continue to operate internationally, but both continue to be subject to the same difficulties and shortcomings.

Phase Three: Provisions for Participation in Health and Social Care

The third phase of interest in participation is more much directly related to health and social care and the groups particularly associated with it. It is also related to very different pressures for change in health and social care policy and provision. It is reflected in the emergence of specific requirements for user involvement in UK health and social care reform in the 1990s, which was particularly linked with moves to market-led thinking and privatization. In England this was associated with the passing of the National Health Service and Community Care Act and its implementation in 1993. There were equivalent developments in all the UK countries and also in Europe and North America (Topol, 2015). Indeed while timings varied, this can be seen as at least an international, if not a global development. What is particularly significant about this phase of interest in participation, is that it had at least two major sources–and that these were very different in origin and aim. This should remind us of both the complexity of pressures toward participation and their ideological relations and also the potential ambiguity of interest in public and user participation.

The two developments associated with this phase of interest in citizen and user participation were first the international political shift to the right and the emergence of the New Political Right from the 1970s (culminating in the emergence of neoliberal ideology) and second, the development of new social movements, whose origins can be seen in the 1960s. These movements included the Black civil rights, women's, the gay and lesbian [later the Lesbian, gay, bisexual, transgender, queer (LGBTQ)] movements, associated with identity, as well as the green/environmental, animal rights and anti-nuclear/peace movements (Jordan and Lent, 1999; Todd and Taylor, 2004).

The participation offered in UK and other subsequent health and social care reforms offered people the right to comment, complain and to have a say in the management or running of services. There was an increasing emphasis and interest in involvement in monitoring and evaluation, audit and review, developing quality, standard setting and “outcome measures,” in randomized controlled trials and systematic reviews–that is to say, in *organizational* issues.

This reflected the consumerist/managerialist ideology significantly underpinning such state or service system driven schemes for involvement, increasingly rooted in market sector thinking, with involvement effectively being at the level of market research or consultation. While the right to complaint for example in the English Children Act (1989), as well as the NHS and Community Care Act (1990). represented an innovation, it only applied when things had already gone wrong and tended to be experienced as an individualizing and stressful measure (Beresford and Croft, 1993).

If service system and state based pressure for participation has been concerned with eliciting and listening to people's views, the pressure from new social movements has been for political and personal *change* and their direct involvement and *say* in making it happen. A further distinction can also be drawn between these new social movements and traditional "pressure group" or "interest" group politics. This international development which has a long history, has significantly been concerned with advancing the interests of powerful rather than powerless groups. In the context of social policy and social problems, furthermore such pressure groups have tended to be dominated by non-service users, campaigning and speaking on behalf of service users, rather than service users speaking for themselves (Richardson, 1993; Beresford, 2016).

If traditional social movements took as their starting point economic and material concerns, new social movements highlight issues of human and civil rights and identity in post-industrial society. In the context of health and social care this has been most powerfully exemplified by the international disabled people's movement.

The pioneering UK disabled people's movement, for example, challenged traditional understandings of disability, rejected conventional interpretations of it in individualized terms of "personal tragedy" and instead developed a new social model of disability, which highlighting the discriminatory social responses to impairment which "disabled" people in society. Thus such international "user movements" have not just been concerned with resistance to oppressive policies and politics, but also the formulation of their own alternatives (Randle, 1994; Charlton, 1998). Disabled campaigners called for a new approach to understanding, policy and provision based on a philosophy of "independent living" which challenged disabling barriers and supported people with impairments–physical, sensory, or intellectual, to live on as equal terms as possible to non-disabled people (Oliver, 1983, 1990; Charlton, 1998). They placed an emphasis on people speaking for themselves ("self advocacy"), for collective action to support their empowerment through developing their own "user led" and disabled people's organizations' (DPULOs) and on bringing about broader social and political change. Other emerging movements, like that of older people, people with learning difficulties, people living with HIV/AIDS and mental health service users/survivors framed their demands in similar terms, pressing for a direct say in policies and services affecting them, pressing for their own participation in making change.

However, the shared language of involvement of these two often competing and conflicting pressures for participation—consumerist and democratic—disguise fundamental differences between them, which have blurred and confused the issues. While the emergence of service user movements and development of neoliberalism can be seen as having some common origins; notably a reaction against paternalistic top-down state welfare systems, in many other senses they sit at opposite ends of an ideological spectrum. Pressures for privatization and a reduced role for the state bear little relation to service users' calls for democratization and empowerment. The consumerist concerns of the neoliberal state and service system do not sit comfortably with the quest for democratization and empowerment of service users and their allies. Instead they have left many service users feeling that state-led schemes for participation are often tokenistic and ineffectual.

They have instead developed their own focuses for involvement, which they see as more effective and productive than the prevailing concern with consultation and “quality control.”

Key areas which have emerged from service users themselves are user involvement in professional training, learning and education; the development of user led research and knowledge production and the development of user-controlled initiatives and approaches. These have made it possible to:

- Develop the kind of learning and training for health and social care professions consistent with supporting people's rights and needs, informed by and respecting service users' understandings of their identities and worlds (SCIE, 2009);
- Challenge the exclusion and marginalization of their perspectives and experience (Faulkner, 2010);
- Advance the evidence base for the social understandings of service users and the issues they experience which they themselves have developed, rather than being tied solely to other people's interpretations and understandings of them (Beresford and Croft, 2012);
- Develop as service users their own organizations, histories, cultures, collectivities and independent action (Beresford, 2016);
- Develop as service users ideas, policy and practice consistent with their own models and philosophies (Campbell and Oliver, 1996).

While it is important not to overstate the amount of progress made in advancing user involvement in health and social care (and indeed in policies and services beyond), it would also be a mistake to under-estimate its achievements internationally. At the same time, as has already been indicated, progress has often been slow and its implementation hesitant, patchy and contested. Its history is riven with ambiguities and false trails (Ocloo and Matthews, 2016). The rhetoric about involvement has tended always to be in advance of the reality. Some service users talk about “consultation fatigue” and being “all consulted out.” We have perhaps reached a new stage in the development of participation generally and user involvement in healthcare specifically. This is a time of increasing conflict and challenge over the idea and its implementation and is perhaps best framed as a new phase in its development.

Phase Four: Reaction And Renewal

Participatory schemes and initiatives have long tended to include ones rooted in consensus as well as conflict. This has been reflected in the different approaches of different user movements. So, for example, the UK disabled people's movement historically while engaging with existing political structures, was initially much more separatist than for example, the UK survivors movement, which tended to have much closer links with and often to be closely located within the service system (Barnes et al., 1999). The US disabled people's movement was significantly shaped by wounded and disillusioned veterans returning from the Vietnam War, whereas by contrast some mental health service user organizations accepted funding from the big pharmaceutical companies (Charlton, 1998).

There has been a tendency to overlook or fudge inherent contradictions between different approaches to participation; their different aims and underpinning ideas. Instead their various proponents have sought to advance their own agendas and highlighted the practical rather than ideological problems underlying resulting difficulties. But more recently we seem to be entering a new stage in participation and user involvement, where these differences and difficulties have become more evident; positions have seemed to become more polarized and entrenched and, protagonists have emerged as in greater conflict with each other. Thus, for all the talk of the rights and say of the service consumer, in both the US and the UK, for instance, the continuing dominance of neoliberal ideology in social policy has meant that the latter has become increasingly harsh and residual; service users have been increasingly marginalized and disempowered and the two positions have become more and more polarized. It has become increasingly difficult to maintain the sense that formal arrangements for participation can offer people a real say as public services and welfare provision has been increasingly cut back.

This fourth phase, perhaps best described as reaction and renewal, is thus one 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 more regressive welfare policies and service users and their organizations increasingly recognizing this contradiction, both experiencing and recognizing the continuing discriminations, inequalities and exclusions they face and beginning to articulate more independently their own ideas, agendas and campaigns for say and involvement.

This phase has a number of expressions in health and social care, associated with developments on the part of both state/service system policies and approaches to involvement and those of citizens/service users. We can look at each of these in turn, beginning with prevailing approaches based on neoliberal ideology, considering some of the latter's broader consequences and then considering the progress of user-led approaches. The UK offers an advanced case study of this.

Reaction–From the Service System

Since the economic crisis of 2007-8, public policy in the UK has been based on the idea of “austerity” with sharp cuts made in public services, including the NHS and social care particularly and with the implementation of so-called “welfare reform,” based on reducing access to and expenditure on welfare benefits, notably to poor, unemployed and disabled people. The harsh and extreme effects of such policies have been evidenced and highlighted by service users themselves and their user led organizations, their allies and academic research. So far this has had little effect in changing such policy (O'Hara, 2014; Beresford, 2016; Garthwaite, 2016; Beresford and Carr, 2018), which can be seen as much more part of an underpinning neoliberal agenda, than as a response to economic difficulties. Despite the continuing governmental rhetoric extolling user choice and involvement, little if any notice has been taken of the strong and wide-ranging criticisms that there have been of such welfare reform policy, not least from service users themselves.

At the same time, disabled people's and other service users' organizations are facing increasing insecurity, having a greater struggle to continue and, many are closing down. They have long had inferior access to funding and other resources compared with traditional charities and voluntary organizations and this situation now seems to have worsened as funding has declined. Thus, the latest evidence worryingly highlights both that survivor-led organizations in the UK, are seriously declining in numbers, while the same pattern is apparent for ULOs more generally. While some new organizations are emerging, others are having to close or downsize. Over an 18 months period from 2015, more than a quarter of survivor led organizations in England had closed down (Yiannoullou, 2018). So instead of progress being made toward services becoming more democratic, access to their support is increasingly restricted and their control role highlighted.

At the same time, mainstream policy and provision have increasingly been framed in terms of ideas and values inspired by and associated with service users and their quest for more say and control over their lives. Three key expressions of this are the reframing of policy and provision in terms of:

- Self-management
- Peer support
- Recovery

Yet each can actually be seen as the incorporation and co-option of ideas originating with service users and their subversion and realignment with neoliberal values and ideas. Thus self-management in mental health discourse and policy is not so much about "managing" in the sense of being able to regain personal control, but "managing" in the "new managerialist" sense that has come to permeate modern neoliberal social policy. "Peer support" has been institutionalized into the role of "peer support worker." Instead of being based on an alternative user-led paradigm challenging psychiatry. Such roles seem more and more to be framed as lower paid ancillary jobs incorporated into the prevailing values, ideas and structures of psychiatry. They occupy an increasingly ambiguous role as an acceptable face of the system for patients entering it, with minimal say and control over it or their role (Penny and Prescott, 2016; Penny, 2018). The idea of "recovery" has been advanced in official policy as challenging the historic writing-off of mental health service users as permanently damaged, dependent and unreclaimable. But it is actually often tied to a bio-medical model. It does not take long to work out that if someone is seen as "recovered" then the support they have received may also be seen as no longer necessary. The reality has been that the idea of recovery has been bound up in neoliberal psychiatric thinking with "restoring" or more accurately, pressurizing service users into employment as a primary focus (Gadsby, 2015).

The Neoliberal Context of User Involvement and Its Wider Implications

The reality is that while the policy atmosphere is one that seems sensitive to and supportive of user involvement and developments associated with it, there is little effective support for it; policy's direction of travel is in many ways antagonistic to it and there seem to be fewer resources made available to support it. Thus, for all the talk about PPI, user involvement, public participation and the ways in which they have crept into the political and policy lexicon, there seem to be a series of continuing structural obstacles in the way of them becoming meaningful and effective, which can make up the context for their operation and potential. These apply between us as human beings, for example,

- As service workers and service users; in neoliberal contexts that are increasingly disempowering for both (Giroux, 2008; Crouch, 2011);

- As practitioners/field workers and managers in increasingly hierarchical controlling structures (Doolin and Lawrence, 1997; Kirkpatrick et al., 2005);
- 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 (Rogers and Pilgrim, 2014);
- As general 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 (Beresford, 2016; Garthwaite, 2016);
- 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 the traditional valuing of conventional randomized controlled trials (RCTs) and systematic reviews (Beresford, 2003; Rose, 2018);
- 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 (Williams, 1989; Beresford, 2013).

The more recent trend in public policy has been to reinforce these divisions and exclusions through the tendency under neoliberalism to increased poverty and inequality. While the post-war UK welfare state increasingly struggled to overcome such 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” (O'Hara, 2014; Beresford, 2016).

Renewal-from Service Users

Although the dominance of neoliberal ideology has certainly imposed limits on the development of user involvement and citizen participation, as well as on the rights and say of people as service users, it would be wrong to assume that it has killed progress. Indeed, what we can see is an increasing focus and indeed in some ways, a strengthening and redirection of activity. Thus, welfare service users in the UK, and indeed elsewhere, while coming under particular attack from welfare reform policies, have been in the lead in challenging such developments, often providing both the evidence and the impetus for this challenge (Beresford, 2012). Thus, while experiencing much suffering in recent years, service users and their organizations have extended both their critiques and their action in relation to health and social care and other policies and services. Some key areas of activity include:

- Widening involvement and campaigning, challenging exclusions
- Involvement in professional and occupational training;
- Involvement in research and knowledge production
- The development of “Mad Studies.”

It is these that are the focus of this last part of the article.

Widening Involvement and Campaigning, Challenging Exclusions

As we have seen the challenging of institutionalized discrimination and exclusions in society began with the emergence of new social movements in the 1960s and 1970s. This was extended through the self-organization of service users through the creation of user led organizations (ULOs) from the 1970s. Here some of the most marginalized, disempowered and excluded 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-organization. As their early organizations 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 analyzed these oppressions through the lense of intersectionality and began to challenge them, themselves.

Beginning with the disabled people's movement, service users, have long highlighted that conventional approaches to participation tend to exclude many groups and individuals. While they have worked hard to make people's involvement more accessible and inclusive, highlighting environmental, communication and cultural barriers, these continue to operate.

Eurikha, a global project which seeks to privilege the rights and perspectives of people who experience distress, is beginning to highlight both the marginalization of the Global South in such developments and also the marginalization of black and minority ethnic communities in the Global North (https://www.eurikha.org/about/). While the United Nations convention on the rights of persons with disabilities has begun to have an impact on disability legislation, policy and practice globally, the response to it has been qualified in some countries and there have been significant limits to how participatory its implementation has been.

The history of the UK disabled people's movement is one that has increasingly highlighted and challenged exclusions and discriminations. Most recently people with long term conditions have asserted their particular difficulties and right to be involved. Service users themselves have also highlighted the ways in which social media and networking can challenge such barriers (as well as reinforcing them) (Onions et al., 2018). A study by the user led organization and network Shaping Our lives, has evidenced the way in which diverse involvement is restricted. It identified big barriers in the way of five major groups, but also strategies to overcome them. Such groups of service users are excluded according to:

- Equality issues; on the basis of gender, sexuality, ethnicity, class, culture, belief, age, disability and so on
- Where they live; if they are homeless, travelers, in prison, in welfare institutions, refugees and so on
- Communicating differently; they do not speak the prevailing language, it is not their first language, they are (D)deaf and used sign language, etc.
- The nature of their impairments; where these are seen as too complex or severe to mean they could or would want to contribute
- Where they are seen as unwanted voices; they do not necessarily say what authorities wanted to hear, are seen as a problem, disruptive etc. These includes neuro-diverse people and people affected by dementia (Beresford, 2013).

Involvement in Professional and Occupational Training

Involving service users (and family carers) in professional and occupational education and training has long been seen as one of the most effective ways of improving the nature and culture of social work and other helping practice and services. *PowerUs*, a partnership of social work educators and service users and their organizations, which already involves twelve countries, within and beyond Europe, 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 and discriminated groups in society (http://powerus.eu). The “gap-mending” process began at Lund University in Sweden in 2005 is a method of teaching that 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 who also have “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. Key gaps that the approach has identified include between, needs and resources; the priority social work demands and the priority it is given; service users and providers, “expert” and experiential knowledge; social work education and practice–and researchers and research subjects (Askheim et al., 2017).

Involvement in Research and Knowledge Production

Research has been the site of one of the most complex and contentious struggles between service users and neoliberal ideology. Its origins can be seen to lie in the struggles first of feminists and then disabled people—to challenge the “epistemic violence” and exclusion we referred to earlier, from the 1970s and regain control over their “experiential” knowledge—the knowledge's that comes out of people's individual and collective lived experience. They called into question the values of distance, neutrality and objectivity of conventional 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 have questioned the independence of mainstream/conventional research, seeing it as frequently following from government/commercial priorities and ideology for funding and often tied to the values and assumptions of the service system.

The UK disabled people's movement condemned existing disability research in the 1970s as biased and on the side of the service system that controlled their lives. To counter this, they developed their own “emancipatory disability research,” which prioritized the equalizing of research relationships, the empowerment of disabled people and the achievement of social change to support their rights and needs (Barnes and Mercer, 1999). The survivor movement developed survivor research along the same lines. At the same time existing research structures began to show an increasing interest in involving research subjects in research process, framed in the UK in terms of “public, patient involvement” or PPI and elsewhere in similar terms. For some time there has seemed to be some convergence between these two developments. There are reports from the mainstream of the progress being made in patient and public involvement in health research, with for example the development of a global network (Staniszewska et al., 2018). But increasingly tensions have emerged between the consumerist/managerialist aims of such involvement in much mainstream psychiatric and other health research under neoliberalism and the emancipatory goals of mental health service users/survivors (Rose et al., 2018). Thus PPI is coming under increasing attack as “centered on a construction of the abstract, rational, compliant, and self-managing patient” under neoliberalism (Madden and Speed, 2017).

The Development of “Mad Studies”

Finally we turn to the emergence of “Mad Studies” because it brings together many of the progressive aims and aspirations of service users in relation to health, social care and other areas of professional activity, highlighting the possibility of building alliances between different stakeholders to achieve these aims. 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 (Le Francois et al., 2013). What generally seems to define the key elements of mad studies is that:

- First, it is definitely divorcing us and itself from a simplistic biomedical model, making possible a necessary rupture from it. It allows other understandings and disciplines to come into it instead of solely medical dominance—sociology, anthropology, social work, cultural studies, feminist, 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 just be talking from nowhere, as if you had no place in the proceedings—as it has been in psychiatry.

- And finally 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, and so on, 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 research and development (Beresford and Russo, 2016).

Conclusion

The aim of this discussion has been to put public and user involvement in health and social care into broader historical, theoretical and philosophical context; to explore competing approaches to it and to chart positive progress in advancing more inclusive and diverse involvement, knowledge and co-production through exploring both emerging barriers and helpful case studies challenging them. This approach has highlighted the tendency for such involvement to be reified and abstracted; treated in isolation, separated-particularly from its ideological and political relations. Yet its history and particularly its recent history with ideological conflict increasing in this field, points to the inadequacy of such thinking. The greatest challenge to this has come from service users and their user led organizations and first hand knowledge production. While user involvement and PPI in health and social care have been conspicuous in their development, with many positives to be seen and important initiatives developed, significant inequalities and inconsistencies continue to emerge between state and service user led approaches. These have acted as barriers to both progress and the inclusion of diversity.

Therefore, key recommendations to achieve more effective and inclusive participation are to:

- strengthen the funding basis of user led organizations, which have played a key role in user involvement innovation, to ensure that they are viable and sustainable (ULOs);

- ensure that both ULOs and service-led schemes for user involvement/PPI are adequately resourced to be more inclusive and address diversity with greater equality;

- Equalize access to funding for user controlled research, particularly within ULOs, to support the development of service user experiential knowledge and to challenge the traditional dominance of so-called “expert” or professional knowledge.

We are in the very midst of change—more advanced in some settings, some nations and with some politics than others. But nonetheless it would be very difficult to argue that health, social care and their service users have not already benefitted from the insights, learning and progress so far achieved. Directing our efforts to advance and monitor such progress, whatever the state of play in our own locality and situation, is likely to be an important and worthwhile activity and goal.

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The author confirms being the sole contributor of this work and has approved it for publication.

Conflict of Interest Statement

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Abel-Smith, B., and Townsend, P. (1965). *The Poor and the Poorest, A New Analysis of the Ministry of Labour's Family Expenditure Surveys of 1953-54 and 1960*. LSE Occasional Papers on Social Administration No. 17, London, G. Bell and Sons.

Anaya, S. J. (2004). *Indigenous Peoples In International Law, 2nd Edn.* Oxford, Oxford University Press.

Google Scholar

Arnstein, S. (1969). A ladder of citizen participation. *J. Am. Inst. Plann.* 35, 216–24. doi: 10.1080/01944366908977225

CrossRef Full Text | Google Scholar

Askheim, O. P., Beresford, P., and Heule, C. (2017). 'Mend the gap' – strategies for user involvement in social work education. *Soc. Work Educ.* 36, 128–140. doi: 10.1080/02615479.2016.1248930

CrossRef Full Text | Google Scholar

Atkinson, A. B. (1983). *The Economics of Inequality*. Oxford: Clarendon Press Oxford University Press.

Google Scholar

Barnes, C., and Mercer, G. (eds.). (1999). *Doing Disability Research.* Leeds: The Disability Press; University of Leeds.

Google Scholar

Barnes, M., Harrison, S., Mort, M., and Shardlow, P. (1999). *Unequal Partners: User Groups and Community Care*. Bristol: The Policy Press.

Google Scholar

Beresford, P. (2003). *It's Our Lives: A Short Theory of Knowledge, Distance and Experience*. London: Citizen Press in association with Shaping Our Lives.

Beresford, P. (2012). From ‘Vulnerable’ to vanguard: challenging the coalition. *Soundings* 50, 46–57. doi: 10.3898/136266212800379509

CrossRef Full Text | Google Scholar

Beresford, P. (2013). *Beyond the Usual Suspects: Towards inclusive User Involvement–Research Report*. London: Shaping Our Lives.

Beresford, P. (2016). *All Our Welfare: Towards Participatory Social Policy*. Bristol: Policy Press.

Google Scholar

Beresford, P., and Beresford, S. (1984). *A Say In The Future: Planning, Participation and Meeting Social Need, 2nd Edn*. London: Battersea Community Action.

Beresford, P., and Carr, S. (2018). *Social Policy First Hand: An International Introduction to Participatory Social Welfare*. Bristol: Policy Press.

Google Scholar

Beresford, P., and Croft, S. (1993). *Citizen Involvement: A Practical Guide for Change*, 1993. Basingstoke: Macmillan.

Beresford, P., and Croft, S. (2012). *User Controlled Research: Scoping Review, London, NHS National Institute for Health Research (NIHR) School for Social Care Research*. London: London School of Economics.

Beresford, P., and Russo, J. (2016). Supporting the sustainability of Mad Studies and preventing its co-option. *Disabil. Soc.* 31, 270–274. doi: 10.1080/09687599.2016.1145380

CrossRef Full Text | Google Scholar

Branfield, F., Beresford, P., with Andrews, E. J., Chambers, P., Staddon, P., Wise, G., et al. (2006). *Making User Involvement Work: Supporting Service User Networking and Knowledge.* York: Joseph Rowntree Foundation; York Publishing Services.

Google Scholar

Campbell, J., and Oliver, M. (1996). *Disability Politics: Understanding Our Past, Changing Our Future*. London: Routledge.

Google Scholar

CDP (1977). *Gilding The Ghetto: The State and the Poverty Experiments, Location Not Known*. Nottingham: Community Development Inter-Project Editorial Team.

Charlton, J. I. (1998). *Nothing About Us Without Us: Disability, Oppression and Empowerment*. Oakland, CA: University of California Press.

Google Scholar

Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., et al. (2011). Service user involvement in cancer care: the impact on service users. *Health Expect.* 14, 159–169. doi: 10.1111/j.1369-7625.2010.00627.x

PubMed Abstract | CrossRef Full Text | Google Scholar

Craig, G., Mayo, M., Popple, K., Shaw, M., and Taylor, M. (eds.). (2011). *The Community Development Reader: History, Themes and Issues*. Bristol: Policy Press.

Google Scholar

Crouch, C. (2011). *The Strange Non-Death of Neo-Liberalism*. Cambridge: Polity Press.

Google Scholar

Davies, C., Wetherell, M., and Barnett, E. (2006). *Citizens At The Centre: Deliberative Participation in Healthcare Decisions*. Bristol: Policy Press.

Google Scholar

Dennis, N. (1972). *People And Planning: The Sociology of Housing in Sunderland*. London: Faber and Faber.

Dolan, P., Cookson, R., and Ferguson, B. (1999). Effect of discussion and deliberation on the Public's views of priority setting in healthcare: focus group study. *Br. Med. J.* 318, 916–919.

Google Scholar

Doolin, B., and Lawrence, S. (1997). Managerialism, information technology and health reform in New Zealand. *Int. J. Public Sect. Manag.* 10, 108–122. doi: 10.1108/09513559710156742

CrossRef Full Text | Google Scholar

Faulkner, A. (2010). *Changing Our Worlds: Examples of User Controlled Research in Action*. Eastleigh: NIHR INVOLVE.

Fishkin, J. (2011). *When The People Speak*. Oxford: Oxford University Press.

Google Scholar

Fishkin, J., and Laslett, P. (eds.). (2003). *Debating Deliberative Democracy*. Oxford: Wiley-Blackwell.

Google Scholar

Fricker, M. (2007), *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

Gadsby, J. (2015). *The Recovery Star Meets The Unrecovery Star, Critical Mental Health Nurses' Network, October 19th, CMHNursing*. Available online at: https://criticalmhnursing.org/2015/10/19/the-recovery-star-meets-the-unrecovery-star/.

Garthwaite, K. (2016). *Hunger Pains: Life Inside Foodbank Britain*. Bristol: Policy Press.

Google Scholar

Giddens, A. (1994). *Beyond Left and Right: The Future of Radical Politics*. Cambridge: Polity Press.

Google Scholar

Giroux, H. (2008). *Against the Terror of Neoliberalism: Politics Beyond the Age of Greed*. Colorado: Paradigm Publishers.

Google Scholar

Goldstein, R. J. (1983). *Political Repression In 19th Century Europe*. London: Routledge.

Google Scholar

Halsey, A. H. (ed.). (1972). *Trends In British Society Since 1900: A Guide to the Changing Social Structure of Britain*. Basingstoke: Palgrave MacMillan.

Google Scholar

Held, D. (1996). *Models of Democracy, 2nd Edition*. Cambridge: Polity Press.

Jordan, T., and Lent, A. (eds.). (1999). *Storming The Millennium: The New Politics of Change*. London: Lawrence and Wishart.

Google Scholar

Kirkpatrick, I., Ackroyd, S., and Walker, R. (2005). *The New Managerialism And Public Service Professions: Change in Health, Social Services and Housing*. Basingstoke: Palgrave.

Google Scholar

Le Francois, B. A., Menzies, R., and Reaume, G. (eds.). (2013). *Mad Matters: A Critical Reader in Canadian Mad Studies.* Toronto, ON: Canadian Scholars Press.

Google Scholar

Ledwith, M. (2016). *Community Development in Action: Putting Friere Into Practice*. Bristol: Policy Press.

Liegghio, M. (2013). “A denial of being: psychiatrization as epistemic violence,” in *Mad matters: A Critical Reader in Canadian Mad Studies*, eds B. A. Le Francois, R. Menzies, and G. Reaume (Toronto, ON: Canadian Scholars Press), 122–129.

Loney, M. (1983). *Community Against Government: British Community Development Project, 1968–78, (Studies in Social Policy and Welfare)*. London: Heinemann Educational Books.

Madden, M., and Speed, E. (2017). Beware zombies and unicorns: toward critical patient and public involvement in health research in a neoliberal context. *Front. Sociol.* 2:7. doi: 10.3389/soc.2017.00007

CrossRef Full Text | Google Scholar

Marshall, T. H. (1950). *Citizenship and Social Class and Other Essays*. Cambridge: Cambridge University Press.

Minkowitz, T. (2018). “Dreams of justice,” in *Social Policy First Hand: An International Introduction to Participatory Social Welfare*, eds P. Beresford and S. Carr (Bristol: Policy Press), 257–261.

Moini, G. (2011). How participation has become a hegemonic discursive resource: towards an interpretivist research agenda. *Crit. Policy Stud.* 5, 149–168. doi: 10.1080/19460171.2011.576524

CrossRef Full Text | Google Scholar

Ocloo, J., and Matthews, J. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual. Saf.* 25, 626–632. doi: 10.1136/bmjqs-2015-004839

PubMed Abstract | CrossRef Full Text | Google Scholar

O'Hagan, M. (1993). *Stopovers on My Way Home From Mars: A Journey Into the Psychiatric Survivor Movement in the USA, Britain and the Netherlands*. London: Survivors Speak Out.

O'Hara, M. (2014). *Austerity Bites: A Journey to the Sharp end of Cuts in the UK*. Bristol: Policy Press.

Google Scholar

Oliver, M. (1983). *Social Work And Disabled People*. Basingstoke: Macmillan.

Google Scholar

Oliver, M. (1990). *The Politics of Disablement*. Basingstoke: Macmillan and St Martin's Press.

Google Scholar

Oliver, M., and Barnes, C. (1998). *Disabled People and Social Policy: From Exclusion to Inclusion*. London: Longman.

Onions, P., O'Neill, R., Kelly, F., and Machin, K. (2018). “Pat's Petition: The emerging role of social media and the internet,” in *Social Policy First Hand: An International Introduction to Participatory Social Welfare*, eds P. Beresford and S. Carr (Bristol: Policy Press), 332–335.

Paxton, P., Bollen, K. A., Lee, D. M., and Kim, H. J. (2003). A half-century of suffrage: new data and a comparative analysis. *Stud. Comp. Int. Dev.* 38, 93–122. doi: 10.1007/BF02686324

CrossRef Full Text | Google Scholar

Penny, D. (2018). “Who gets to define ‘peer support’?” in *Mad In America*. Available online: https://www.madinamerica.com/2018/02/who-gets-to-define-peer-support/.

Penny, D., and Prescott, L. (2016). “The co-optation of survivor knowledge: the danger of substituted values and voice,” in Searching For A Rose Garden; Challenging psychiatry, fostering mad studies, eds J. Russo and A. Sweeney (Ross-on-Wye: PCCS Books), 35–45.

Randle, M. (1994). *Civil Resistance*. London: Fontana Press.

Google Scholar

Richardson, J. J. (ed.). (1993). *Pressure Groups,*. Oxford: Oxford University Press.

Rogers, A., and Pilgrim, D. (2014). *A Sociology of Mental Health and Illness, 5th Edn*. Maidenhead: Open University Press; McGraw Hill Education.

Google Scholar

Rose, D. (2018). “Renewing epistemologies: service user knowledge,” in Social Policy First Hand: An *International Introduction* to *Participatory Social Welfare*, eds P. Beresford and S. Carr (Bristol: Policy Press), 132–141.

Rose, D., Carr, S., and Beresford, P. (2018). Widening cross-disciplinary research for mental health: what is missing from the Research Councils' UK mental health agenda?. *Curr. Issues Dis. Soc.* 33, 476–481. doi: 10.1080/09687599.2018.1423907

CrossRef Full Text | Google Scholar

Russo, J., and Beresford, P. (2015). Between exclusion and colonisation: seeking a place for mad people's knowledge in academia. *Dis. Soc. Curr. Issues* 30, 153–157. doi: 10.1080/09687599.2014.957925

CrossRef Full Text | Google Scholar

SCIE (2009). *Building User And Carer Involvement In Social Work Education, At A Glance 19*. London: Social Care Institute for Excellence.

Shaping Our Lives (2018). *Open Letter to the Organisers of the Global Ministerial Mental Health Summit, 9-10 October 2018*. London: Shaping Our Lives. Available online at: http://bit.ly/2A1xtDu accessed 31 October 2018.

Sheffield, R., and Rector, R. (2014). *The War On Poverty After 50 Years. The Heritage Foundation*. Available online at: https://www.heritage.org/poverty-and-inequality/report/the-war-poverty-after-50-years.

Smith, H. L. (2014). *The British Women's Suffrage Campaign 1866-1928*. London: Routledge.

Google Scholar

Staley, K. (2009). *Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research, October*. Eastleigh: NIHR INVOLVE.

Staniszewska, S., Denegri, S., Bagley, H., Hickey, G., and Morley, R. (2018). *Moving Forward With Global Patient and Public Involvement in Research, Cochrane Community Blog, Cochrane Community*. Available online at: https://community.cochrane.org/news/moving-forward-global-patient-and-public-involvement-research.

Titmuss, R. M. (1968). *Commitment to Welfare*. London: George Allen and Unwin.

Google Scholar

Todd, M. J., and Taylor, G. (eds.). (2004). *Democracy and Participation: Popular Protest and New Social Movements*. London: Merlin Press.

Topol, E. J. (2015). *The Patient Will See You Now: The Future of Medicine Is in Your Hands*. New York, NY: Basic Books.

Google Scholar

Tritter, J. Q., and McCallum, A. (2006). The snakes and ladders of user involvement: moving beyond arnstein. *Health Policy* 76, 156–168. doi: 10.1016/j.healthpol.2005.05.008

PubMed Abstract | CrossRef Full Text | Google Scholar

Wilcox, D. (1994). *The Guide to Effective Participation*. York: Joseph Rowntree Foundation.

Google Scholar

Williams, F. (1989). *Social Policy: A Critical Introduction, Issues of Race, Gender and Class*. Cambridge: Polity Press.

Williams, M. (2004). Discursive democracy and new labour: five ways in which decision-makers manage citizen agendas in public participation initiatives. *Sociol. Res.* 9, 1–17. doi: 10.5153/sro.949

CrossRef Full Text | Google Scholar

Yiannoullou, S. (2018). *Chief Executive, National Survivor User Network, Reporting on NSUN Survey.* London: Personal Communication.

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