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## **Extending Voice and Autonomy through Participatory Action Research: Ethical and Practical Issues**

### **Reflections on a Workshop held at Durham University, November 2018**

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### **Abstract**

Participatory Action Research always operates in the tension of extending the voice of people who are marginalised and unheard in the society. A workshop, *'Extending Voice and Autonomy through Participatory Action Research: Ethical and Practical Issues'*, was therefore organised to look at the issues arising from this tension. The workshop aimed to examine critically the potential of participatory action research to enable people whose voices are seldom heard and choices are often restricted to be seen, heard and to influence practice and policy relevant to their lives. The paper first outlines the rationale for the workshop and then demonstrates how 'co-impact' of participatory action research projects can be achieved through having conversations and reflecting on the ideas of 'voice and autonomy', 'knowledge', 'vulnerability', 'user involvement and participation'. Through reflecting on the experience of preparing for and delivering the workshop, we seek ways to transform the relationship(s) between service users/community partners and academic and service professionals in the hope of generating practical knowledge ethically.

### **Key words**

Participatory action research, autonomy, ethics

## Background

This paper offers a reflective account of some of the issues raised at a workshop, *'Extending Voice and Autonomy through Participatory Action Research: Ethical and Practical Issues'*, organised by Durham University's Centre for Social Justice and Community Action in partnership with *Ethics and Social Welfare* journal in November 2018. The workshop aimed to examine critically the potential of participatory action research to enable people whose voices are seldom heard and choices are often restricted to be seen, heard and to influence practice and policy relevant to their lives. In this article we use a range of terms to refer to people with direct experience of the issues being researched including 'service users' and 'experts by experience'. Meanwhile, 'community partners' is also employed as a term that emphasises people's partnership with academics, rather than their specific experiences, when doing research. These terminologies reflect the different roles that people may play in the research process, as well as the plethora of identities developed in different disciplines where a participatory approach has been adopted<sup>1</sup>. It is important to note that no presented term is without limitations, and the choice of terminologies in different sections in this article is made by the author(s) who wrote those sections. On the one hand, the different terms reflect the specific disciplinary traditions, while on the other hand, they serve as an indicator of how power has been held by disciplinary professionals (Carr, 2007) through the ways people with experience of the issue under study/of concern are represented and positioned in different collaborative endeavours.

Participatory action research (PAR) involves people with direct experience or interest in the topic under study in all or some of: research design, data collection, analysis, dissemination and implementation, with a view to creating social change. It may be undertaken by service users/members of community groups by themselves, or in collaboration with 'professional' researchers. PAR is increasingly popular as community-based groups desire to highlight priority needs to target scarce resources and advocate for policy change for the benefit of people on the margins of society. Funders are also concerned that research has a social and economic impact, and the direct involvement of community-based researchers in PAR enhances the likelihood of benefits to society and economy beyond academia.

While 'impact' is mostly understood as the end-product of research projects, Banks et al. (2017) argue for the need to achieve 'co-impact' that includes 'participatory impact' (e.g. changes in emotions, thinking and practices of co-researchers), 'collaborative impact' (e.g. use of the findings by individuals or organisations to change practice and policy) and 'collective impact' (e.g. deliberate strategies by research partners in making changes to targeted policy and practice to address issues highlighted by the research they are undertaking). Co-impact defies 'a linear process, based on a donor-recipient model' in favour of 'micro process-based

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<sup>1</sup> In UK's context, the term 'service users' is majorly adopted by social policy and social work research to reflect the lack of participation of users in service design and delivery (Croft and Beresford, 1996). This terminology is criticised for being consumerist (Carey, 2009) and excluding people with relevant experiences but do not want to use services. Expert by experience (EBE) is in part an attempt to include any one who has experienced, for example mental health distress, irrespective of their use of services, and those who support this group (family and friends). However, some people object to the use of 'expert' and the universality of 'experience'. Community partner is also an attempt to 'move away from the "outside expert" and tokenistic involvement' to place importance on negotiation situated in specific socio/cultural/political contexts where the collaboration takes place (Durham Community Research Team, 2011:7). However, what constitutes a community is always debatable.

impacts that include changes in the thinking and practices of co-researchers' (Banks et al, 2017, p.541). This paper demonstrates how understandings of the 'co-impact' of participatory action research projects unfolded during the workshop. Workshop coordinators and facilitators revised their understandings of voice and autonomy, and of what counts as knowledge, 'vulnerability', 'user involvement and participation' while preparing, delivering and reflecting on their experiences of running the workshop.

### **Rationale for the workshop: ideas, concerns and changes in the process**

The idea for the workshop was inspired by the Norwegian project, 'Challenges of Participation when Service Users' Autonomy is Challenged/Restricted in Health and Welfare Services (CHAPAR)' (2018-2022) (<https://app.cristin.no/projects/show.jsf?id=642284>). This project recognises that autonomy and participation of service users can be restricted by blunt policy understandings, which misrepresent the 'practice reality' of user participation, and the involuntary involvement of people in health and social services, e.g. young immigrant refugees in Norway. Starting with the idea of 'restricted autonomy', the planning group from the Centre for Social Justice and Community Action (CSJCA) proposed a closer exploration of the barriers to service users/community partners' participation in undertaking research with service practitioners and academics and possible ways of overcoming them.

However, despite the potential that the concept of 'restricted autonomy' might have for revealing and transforming the relational conditions (person-in-interactions, person-in-institution/organisation and person-in-culture) that curtail people's choices, members of CSJCA planning the workshop felt that there may be a risk of reinforcing the assumption that some people naturally have less autonomy than others (taking 'autonomy' to mean ability to make choices and decisions). Ethical concerns were raised about the potential labelling and stigmatising effect that this may have on community partners involved in the workshop, reproducing a power hierarchy that might undermine the autonomy of community partners instead of supporting equal partnership in making sense of voice and autonomy. These ethical concerns led to a long discussion within the workshop planning group from the CSJCA, about the multiple meanings of 'autonomy', and the importance of seeing autonomy as 'relational' rather than 'restricted'. The concept of 'relational autonomy', which is discussed in more detail in the article in this issue by McLaughlin based on her keynote presentation at the workshop, sees people's capacity to make choices as individuals as linked to their dependence on and/or interaction with others (McLeod and Sherwin, 2000). This seemed a more positive approach to framing the workshop than the concept of 'restricted autonomy'.

### **Participatory Action Research (PAR) for extending voice and autonomy**

The workshop was introduced by Banks and Kong. They explained that the ideal of participatory action research is to address inequality by involving people experiencing marginalisation, whose voices are often silenced or unheard, in the process of knowledge-making and problem-solving. PAR was inspired by, and draws on, critical pedagogy (Freire, 1972), international and community development (e.g. Banks et al., 2019; Hall et al, 2015), feminist theories and practice (e.g. Maguire, 1987) and tribal and indigenous research (e.g. Smith, 2012). It seeks changes through democratic, participatory, empowering and educational processes. Therefore, PAR aims to challenge established power hierarchies through sharing power in knowledge production, using knowledge for collective action and building partnerships with people in communities that are often easily ignored.

Approaching social change from the perspective of people with experience of being marginalised and silenced, PAR has driven a more contextualised understanding of autonomy and may challenge injustices embedded in everyday life (e.g. Kong, 2017; Ho, Kong and Huang, 2018; Banks, Carter and Herrington, 2013; Banks et al., 2017). Projects conducted by members of community-based groups and organisations with Kong and Banks have demonstrated this possibility. For example, a project in Hong Kong supported abused women and their children and transformed ‘mothering’ practices into mutual care practices, acknowledging both the agency of children in offering care and the need for care of abused mothers. A collaborative research project in the Teesside area of the UK aimed to promote the financial autonomy of some of the participants through including a mentoring scheme alongside evidence gathering for research and campaigning.

### **Relational autonomy – as concept and feeling**

While traditional conceptions of autonomy tend to focus on the capacity of individuals to make decisions, the workshop was concerned to explore alternative conceptions of autonomy as exercised in relationship with other people, which fit better the nature and aims of participatory action research. The concept of ‘relational autonomy’ was introduced and explored by Janice McLaughlin as keynote speaker, and this is discussed in depth in her article in this issue, specifically in relation to participatory research by and with children and young people. The concept of relational autonomy has been developed particularly by feminist theorists (see McLeod and Sherwin, 2000), and entails recognizing that autonomy is both defined and pursued in a social context (including structures of oppression) and this influences the opportunities an individual has to develop and exercise autonomy.

Following table discussions reflecting on the themes of the keynote speaker, participants undertook a practical activity (‘Picturing Autonomy’) to explore relational autonomy using visual methods. This was facilitated by Jen Thompson, drawing on an approach developed by the McGill University Participatory Cultures Lab (see Vanner et al., 2019), participants worked individually or in pairs to take photos of their hands and write messages on the photos about autonomy. The photos were developed on a portable printer and displayed to provoke further reflection and discussion on the embodied and visual representations of relational autonomy (see Figure 1).



Figure 1: An activity called Picturing Autonomy invited participants to explore concepts of autonomy by photographing messages with their hands.

## **Workshop discussions and practices**

In workshops various groups explored further the opportunities and challenges PAR can bring to extending people's voice and autonomy. The workshop facilitators offer their reflections on their PAR projects and their experiences facilitating workshops below.

### **Mad people interviewing mad people**

This workshop (facilitated by Toby Brandon) exposed the fears government institutions might have in supporting participatory projects carried out with partners who have experienced mental health distress.

The workshop was run in the style of a large conversation, where themes around the critical understanding of mental health and research were presented and discussed in the round. The conversation was influenced by work in Mad Studies where the existence of traditional medical interpretations of mental health are challenged and replaced with social theory, focusing on power and key narratives (LeFrancoise, Menzies and Reaume, 2013).

The workshop triggered a number of interesting conversations around the shared frustration of attempting to mould participatory research ethical applications (Cook, Brandon, Zonouzi and Thomson, 2019) to fit the requirements of the UK National Health Service and other ethical governing bodies. A number of the workshop participants had experienced a lack of flexibility and understanding around the work they were undertaking. There was a shared appreciation of the cultural difference between the accommodating and often holistic ethics of participatory research in contrast to sometimes more rigid and restrictive biomedical governance systems. One concern was expressed over portraying 'experts by experience' as vulnerable and as such problematic, leading to them being patronised. It seemed ironic that an ethical system set up to protect and support a group of people ends up disempowering the very same group.

A mutual appreciation of alternative, more creative ways of expressing opinion and widening understanding in research was also explored. The added value of poetry or drama was considered, not only because it allowed people to express views in different ways but because other mediums may contribute more than traditional text. Drama and poetry can communicate a sense of space, time and feeling in a way that text may not. This gave rise to questions around why we place more credence on particular types and ways of presenting knowledge. The importance of creating more knowledge democracies across all groups and ways of disseminating work was agreed. This was linked to the significance of disruption as an important part of participatory research. The disruption of traditional, more positivistic ways of conducting and valuing research was seen as helpful.

Next the potential for a shift in 'experts by experience' identities was discussed. This is the move from being a patient to a student on a training course and onto being a professional undertaking paid research. On a personal level, this has had a significant positive impact on people's wellbeing and set up role models for the potential involvement of other 'experts by experience'. Interestingly in contrast the training mentioned may have had a negative side effect in potentially disempowering the purity of the 'experts by experience' approach. The question arose of do we really want to train 'experts by experience' to be a new breed of professionals? The concern here was that this training moulds them into a role that obscures some of the added value and skill that their original experience brings. Interesting one 'expert

by experience' had stated that they had not used mental health services for some time and was concerned that this might have affected their authenticity as an expert.

### **Engaging, supporting and working with people through music**

This workshop (facilitated by Sue Shaw and Sam Slatcher) challenged the pessimism propagated through the system of nursing homes by engaging users in celebrating life through music. The workshop focussing on the potential use of music to connect with people marginalised through various conditions and situations, started by sharing the experience of the two presenters. Sam related the use of national and newly written music to engage with and develop a group of Syrian asylum seekers. Performances and a CD have built the group's identity and confidence. Subsequently, the project has grown even further with crowd funding to a stage where a national tour and further development is now possible.

Sue outlined the sometimes dramatic results of singing in care homes and a hospice for those with dementia, which also supports both their carers and staff. Recognition of the value of music is currently growing apace, and the surprise was that all participants, irrespective of their background or work space, had experience of how powerful music can be and also had ideas of how it may be further developed for use in PAR.

It was encouraging to find that participants working in a wide range of settings found a commonality in the response to and effect of music. Music can reach everyone at a fundamental and emotional level, at any age, unwell or healthy, without language or with, and forge connections and meaning that enable and enhance communication and relationship building. It stimulates and relaxes, fosters memory and engagement. It has a universality and opens doors. Its use can bind people together. Above all, it can give joy and meaning.

While the facilitators are exploring the potentials of using music to engage with people in the community, they are also aware of how people with hearing impairment would appreciate other creative ways to enjoy rhythms. If music is for all, seeking ways to extend its boundary beyond musical notes to vibrations and movements (of colours and body) would be always on the agenda for using music in PAR.

### **Making participation real**

This workshop (facilitated by Stewart Chappell, Helen Charnley, Se Kwang Hwang, Danielle Rudd and Nicki Ward) engaged participants in visual thinking and carefully worked through a number of steps for making our research truly participatory. The workshop developed from two separate approaches focussing on the involvement of people with learning disabilities and autism in research. One approach was designed to develop better understanding of: i) what has, or can, be learned from people considered as experiencing 'restricted autonomy', about the ethical conduct of PAR, and ii) what practical steps can be taken to address power imbalances linked to choice of research topics and degrees of involvement and decision-making in the PAR process? The second approach focussed on experiences of research involving people with learning disabilities and autism by simulating the use of the 'PATH' planning model, an inclusive and collaborative approach that may be used in developing participatory action research. PATH (Planning Alternative Tomorrows with Hope) is a tool designed to help individuals and teams with different needs and ideas to set goals and develop a plan, which will help them to meet those goals (Helen Sanderson Associates, 2019).

Combining these two aims, the PATH planning model was used in this workshop to demonstrate the feasibility of using person-centred planning techniques to develop a participatory research project. The workshop was facilitated by Stewart Chappell from Skills for People, a self-advocacy organisation of people with learning disabilities and Nicki Ward from the University of Birmingham. The PATH plan was articulated visually by Danielle Rudd (Skills for People and Northumbria University), as it was developed by workshop participants. Stewart introduced the concept and underpinning principles of PATH planning and his experience of using it as a planning tool. Nicki explained her aspiration to explore the application of the model to develop a PAR project.

**The PATH model** involves seven steps identifying:

1. End goal/s (dreams/visions). The idea here is to avoid negative thinking and being held back by (real or imagined) constraints. 'Let the constraints go' as Stewart repeatedly reminded participants.
2. What must be done to achieve the dream/vision.
3. Who needs to be involved.
4. What information is needed.
5. Necessary skills.
6. Necessary actions.
7. People responsible for taking action.

#### **Research problem: 'cuckooing'**

This research topic, suggested by a workshop participant, concerns people affected by 'county lines', where incomers to an area move into the homes of people they regard as 'vulnerable', pretending to befriend them but then gradually take over their premises to run illicit businesses, typically drug dealing or sexual exploitation. This phenomenon is known as 'cuckooing'. Using the initial stages of the PATH model participants identified: i) an end goal (enabling effective practitioner prevention/intervention), ii) ways of achieving the goal, iii) relevant participants, iv) necessary information. Constructive contributions came from a range of participants. But it was noticeable that academics' perspectives on research were, by and large, heavily influenced by assumptions about (potential, and sometimes imaginary) barriers, despite continual reminders from the facilitator, a practised 'person-centred planner', to focus on goals not problems. The facilitator's continual effort in engaging participants in a different way of thinking ensured that the exercise in using the tool was successful and enabled participants to understand the complexity of participatory research.

PATH offers strong potential for transforming the focus on barriers often held by academics. However, the realisation of that potential depends on the ability of academics to listen to service users/community partners' dreams and goals in life. In the workshop, an academic participant, raising a topic of research with which they had been struggling, walked away with an action plan for developing a research proposal. This experience further shows the importance of seeing participation as bringing diverse experiences and expertise together for problem solving not problem finding and it directly challenges the rationale for academics to monopolise power associated with 'expertise'.

#### **Concluding remarks**



In this workshop, we explored how marginalisation could happen to a number of groups: children in the child protection system; patients in medical systems; refugees in the migration process; older adults in long-term care; and people with learning disabilities and autism in their everyday lives. When a blanket application of 'vulnerability' is employed to justify 'support and protection' for a social group, hierarchies in knowledge and decision-making are also created. These privilege knowledges produced by professionals and through scientific research. Having community partners co-facilitating the workshops, academic practices that give more credence to theoretical knowledge and more weight to 'problem solving' than person-centred development were challenged. Instead of focussing on 'problems' or 'vulnerability', participatory action research projects presented in this workshop found it more helpful to shift the focus to 'celebration of life', 'goals' and 'strengths' (Cooperrider, Whitney et al. 2003) as a means of finding ways to enhance people's autonomy.

By involving people with direct experience or interest in the topic under study, PAR keeps the power of academics and service professionals in check. It persistently requires conversations among participants to take place in order to examine how decisions are made and who get to make them. For example, as we wrote this paper, facilitators reflected on the ways by which the workshop theme was chosen, and the understanding of 'autonomy' was deliberated, suggesting the need for democratisation of leadership in organising community workshops. While we are advocating for involving people with direct experience of an issue in research and leadership, PAR as well keeps participants vigilant towards the silencing effect of professional power and raises questions about the potential for co-optation and institutionalisation of experts by experience. Ultimately, PAR, as both an ideal and practical reality, seeks ways to transform the relationship(s) between 'experts by experience' and academic and service professionals in the hope of generating practical knowledge ethically.

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