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Participatory Research: promoting positive changes for health through the power of collaborative learning

Co-labouring

- ... toil, distress, trouble: exertions of the faculties of the body or mind ... an activity which is at times likely to be uncomfortable.
- (Sumara and Luce-Kapler 1993: 393)

Essential argument

- For change to take place that reflects the knowledges of those who are central to the research issue, the people who know most deeply about the issue— not outsider experts — must be active partners

Epistemic injustice (Fricker 2009)

- Prejudice that leads to deflated levels of credibility
- Lack of shared social resources that make it difficult for people to make sense of their experience and so find it difficult to argue it

PHR: defining characteristics

- seeks to involve those for whom a change will make a difference in:
 - defining research issue
 - designing research approach
 - collaborating in data generation through reflective critique (as a form of self-knowing and collaborative knowing)
 - analysis and meaning making (as above)
 - dissemination and application of the findings of the research

Primary assumption

- “participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research” (ICPHR 2013:5).

FabPos Project Design

- **3 Groups**
 - 5 x 2 hour sessions
 - 3 x discussion sessions/data generation/data analysis
 - 1x call-back discussion session
- **1 x Big Conversation Day – Data generation and Face Validity**

Recursive approach

- “delve beneath our rhetoric (and common understandings into deeper knowing” Cook 2009:288
- “reciprocal perspective taking” (Habermas 1998)

Knowledge

- Knowledge is brought to the research to be disrupted and generated not collected

Different virtues

- Knowing the answer is a passive state. It Requires no decisions, carries no risks and makes no demands. It is overrated
(Duckworth (1996: 64-65))
- Not knowing is seen as a virtue in PHR.

...in the messy area (Cook 2009)

- pushes at boundaries – really makes people think (together)
- digs into tacit underpinnings that frame perceptions of reality
- challenges current orthodoxies: things we currently believe to be vitally important for practice and whose knowledge we value
- pulls apart rhetoric and well rehearsed notions of practice
- leads to the re-examination and sometimes relinquishing of ways of thinking and practising

'Experts' as learners

When I started the course it was right, how will I go about doing this, what do I need to know - to tell folk - but it got me reflecting on loads of different stuff about my practice, and my relationships with families and things like that. ... I learnt loads in the group about myself. People were helping me to recognise personal things... I felt like a participant and the group was really supportive. I got loads out of it, the most being that we can learn so much if we let ourselves. (facilitator 3: Group 3)

The importance of building relationships

- “To try and catch the interpretive process by remaining aloof as a so-called ‘objective’ observer, refusing to take the role of the acting unit is to risk the worst kind of subjectivism – the objective observer is likely to fill in the process of interpretation with his own surmises in place of catching the process as it occurs in the experience of the acting unit which uses it”. (Blumer 1969:86)

Empathy and mutual respect

- I think there's a mutual respect for each other as well. Because as much as we've all got different situations - admittedly [Name]'s situation is probably more different than ours, we can still empathise with it. And she can still empathise with us (Family Carer: Group 3).

Setting the tone

- it is important that we are all honest about how things are working, honest for ourselves and honest about the role of others. If, because we all like each other (laughter) we just say things are fine, then the next family carers that come on this course will get it in the same way as we are doing it now. If it is not working for you then it may well not work for them (Academic researcher)

Comfortable enough for it to be difficult

... comfortable enough to have the serious conversation. And, kind of, being quite open and honest. Kind of, about the difficulties and challenges in our lives. But, on the flip side, kind of... We're also able to chip in with funny bits of stories and... Obviously tag onto other people... Whatever other people are saying. Just to have... You know, that bit of humour and that bit of fun as well". (FC 4, Group 1).

Changing behaviours (2nd dart!)

- I don't just act now – I feel the pain and then I stop and think what I do now will make the difference between a whole day of stress or making something of it – and while I am doing that I am not angry at him – and its like he knows that and the whole thing does not escalate in the same way – the whole house is calmer – and we have not been hit for ages – so that's a bonus. (FC Group 1)

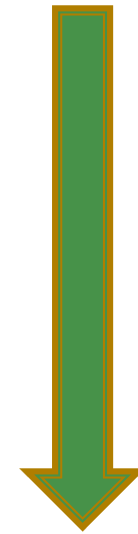
Changing behaviours: the practice

- I think one of the big breakthroughs with this is just the way, together, we've created something. What's been great is doing it together because what we've ended up with is different from what we started off with, it's been, kind of, refined ... we have created something that none of us would have thought of if we had not gone through it... I think the thing that's really struck me is it's so important that it's like this - it's a conversation. It's a conversation and you can't really put a price on, you know, what people bring... What you're bringing to the group. It's so easy for us as professionals to think these are the latest psychological benefits. We should make them available. Which is, you know, a decent start. But how you go about making them available is you do unto them. I think one of the things that we've learnt in this course is you don't do unto them. That's so crucial. So, dismantle the doing unto...the giving and do more taking!

PHR involves

- participatory practices rather than participation
 - voice, power and agency are key issues
- mutual engagement – beyond su research
- relationships
- critical reflection
- cycles for understanding, meaning making and learning
- impact - change

Disruption



Learning

Learning: people with learning disability and behaviour that challenges

- “The more things just got blown into the air, the more fun it was...When we were discussing and debating stuff, during some of the discussion that we had, your mind slipped a few times before it settled. It’s like you started it off and someone would say something and it would be like, “Erm, I’m not quite sure of...” And then it started a bit of a debate up. And then by the time you finished the debate you had most of the answers and then it was like, “Erh.., you know, we’ve just answered it.” (Cook and Inglis 2008. p. 63)

Bibliography

- Abma T, Cook T, Ramgard M, Kleba E, Harris J & Wallerstein N (2017) Social impact of participatory health research: collaborative non linear processes of knowledge mobilization. *Educational Action Research* Vol 25 (4) pp489-505
- Blumer, H.(1969), *Symbolic Interactionism: Perspective and Method*. Berkeley, University of California Press.
- Cook T & Inglis P (2012) Participatory research with men with learning disability: informed consent. *Tizard Learning Disability Review* Vol 12 (2) pp92-101
- Cook T (2009) The Purpose of Mess in Action Research: building rigour through a messy turn. *Educational Action Research* Vol 17(2) pp277-292.
- Duckworth (1996) *The Having of Wonderful Ideas" and Other Essays on Teaching and Learning*. Teachers College Press, 2006
- Fricker M (2009). *Epistemic Injustice: Power and the Ethics of Knowing* Oxford University Press.
- Habermas (1998)
- International Collaboration for Participatory Health Research (2013) Position Paper 1: *What is Participatory Health Research?* Editorial Group: Michael T. Wright, Germany (lead); Irma Brito, Portugal; Tina Cook, UK; Janet Harris, UK; Maria Elisabeth Kleba, Brazil; Wendy Madsen, Australia; Jane Springett, Canada; Tom Wakeford, UK www.icphr.org

Bibliography cont:

- Israel BA, Schulz AJ, Parker EA, Becker AB. (1998) Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review Public Health*. Vol 19: 173–202.
- Rapoport R.N. (1970) Three dilemmas in action research, *Human Relations* 23 (6) pp 499 513.
- Sumara DJ., & Luce-Kapler R. (1993). Action research as a writerly text: Locating co-labouring in collaboration. *Education Action Research* 1 (3) pp 387–96.
- Wallerstein N, Duran B, Oetzel J & Meredith M (Eds) (2017) *Community-Based Participatory Research for Health: Advancing Social and Health Equity*.
- Winter R & Munn-Giddings C (2001) Introduction In Richard Winter & Carol Munn-Giddings (eds) *A Handbook for Action Research in Health and Social Care*. London: Routledge pp 3-8
- Winter, R., (1998), “Finding a Voice –Thinking with Others: a conception of action research”, *Educational Action Research*, Vol (1), pp 53-68