The pleasures and pitfalls of collaborative disability policy research

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Why Collaborate in Disability Policy Research?

Official imperative-
RCUK (2009), SCIE (2009), DH (NIHR) (2009)

Academic and Movement

• Zarb-participatory research (1992)
• Beresford & Croft (1992)-User voice
• Brandon (1991)-Speaking truth to power
• Oliver (1992)-Emancipatory Research
• Charlton (1998)-Nothing About Us Without Us
• Lather (1987)-Reciprocity and gain
• Maguire, (1987)-Participatory action research
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Changing Relations Between Academy and ‘Policy End Users’-A Typology

- **Academic-Driven** convergence of Academic and User Worldviews over time (Norah Fry)
- **Movement-Driven** (Leeds CDS)
- **Policy-Driven** Collaboratives (SPRU, PSSRU)
- **New Activist-Driven** Challenging Academic response and fundable themes? (DPAC, WOWp, Black Triangle)
'The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretive view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs' (Oliver, 1992: 110).
‘Important methodological questions are raised by the act of researching disablement. Disability research has attracted much methodological criticism from disabled people who argue that it has taken place within an oppressive theoretical paradigm and within an oppressive set of social relations. These issues are of heightened significance for non-disabled researchers and bear many similarities to those faced by researchers investigating barriers to the social inclusion of women, Black and ‘Third World’ peoples’

The radical and uncompromising stance adopted by those advocating the emancipatory paradigm confronts the would-be researcher with a daunting task - all the more daunting given that none of the advocates of the paradigm have yet laid claim to the achievement of truly emancipatory research (Priestley and Stone)
Implicit in the literature on disability research is the assumption that as long as disabled people and their organizations handle the reins of disability research, then all will be well. However, this assumption is far from unproblematic, since it apparently ignores the diversity of experience amongst disabled people, in this country and world-wide (Priestley and Stone)
• Involvement a key tenet of much policy research.
• Remains disagreement as to what is involvement-user led, user involved, user-informed?
• Issue of whether we can emancipate?
• Issue or what emancipation means.
• How is the research and policy climate changing?
• Can we survive as researchers and be user-driven?
• How best to undertake robust research with collaborative partners?
Thriving and Surviving at Work (2003)

• A Study of Disabled People’s Employment Experiences and which factors afforded them to thrive and survive at work alongside barriers.
• In focusing on what works we were trying to empower by not simply looking at barriers.
• Mapped 156 disabled workers via scoping questionnaire, 33 in-depth interviews.
• A three-phase, formative [framing] and summative [data verification] focus groups.
• Project reference group in addition to formal Advisory group accountable to funder was adopted.
• Research team [n=4] disabled people [academy, activism, third sector]
Phases 1 and 2 of the research were piloted and every effort was made to provide alternative format questionnaires and appropriately designed interviews. Most interviews were undertaken by telephone. Where speech, hearing impairment or learning difficulties were an issue, face-to-face interviews were undertaken. Disabled people were fully consulted on the development of the research tools used. The research team all identify as disabled people, and members of the Project Advisory Group also ‘represented’ a range of disability, impairment and employment issues.
Issues in Collaboration

• Representative of all?
• Rewarding Involvement.
• Burden of time versus token involvement.
• Non-contractual relations and research.
• Debates over impairment significance.
• Checking models in use and data validity.
• Radical enough in intent and dissemination?
SCIE Working Together Study (2003)

- Study of carer participation in service design, delivery and review
- England, Wales and Northern Ireland
- Systematic review and interviews with carers, senior managers and policy chiefs
- Carer reference groups—one local to research hub and one national [policy leads, practice leads]
- Carers involved with everything including interrogating the term carer, scrutiny of research tools, through being trained as interviewers and data analysts through to data verification, research dissemination [SCIE and PRTC]
Challenges

• “You’re not supposed to talk to carers, you’re a disability researcher”
• Carers wanted to tear up the brief. Funder set the initial parameters
• Gentle art of compromise
• Training needs analyses. Matching carer researcher to roles/preferences
• Love of respite, reducing ‘carer burden’
• Frustration between carers and policy inertia
• Dissemination-preaching to converts
DH Evaluation of PSA 16 Employment Projects

- Pathways to Work and Housing for people with enduring MH Problems and LDs
- Steering group
- Formative focus groups with organisations and service users
- A key plank of the evaluation was that of an organisational self-evaluation approach which assessed both the value-added to project participants.
Study Principles

• Cooperative venture- Not an *us and them* scrutiny type approach
• Acknowledging Diversity- Impairment, provider, local socio-economic context
• Mutli-Layered- Aiming to tap into multiple voices- organisational, service user and staff)
• Robust- Differing forms of evidence were cross-referenced to afford a robust verification of project evaluation data
Positive Collaborations

- Strong research relationship with providers and service users
- Oppositional stances given space
- DH were open to formatively derived self evaluation tools
- The study assessed intra and inter-provider activity, thus collaboration can be understood at many levels
- Powerful dissemination structure to influence regional policy
Example of Collaboration

- Tees & Esk Valley Mental Health Trust and Forwards Employment Project
- Innovation funding (PSA 16) allowed joint approach to reducing worklessness for people with enduring/challenging MHPs
- Co-location, notes sharing, professional ‘remarcation’
- Job matching, job carving
- ‘Place and Train’ philosophy
- Early intervention in relapse
Challenges

• Provider response was patchy.
• Marketised context. Competing NGOs.
• Evaluation can ‘name and shame’. Future dynamics?
• Socio-Economic Context has to be accounted for.
• Relapse in mental health requires flexibility when funded is time-limited
• Inter-sectional comprehension-BME, culture
• Diplomacy where service users and providers brought together-commensurate worldviews?
To Conclude

- Collaboratives and Partnerships in Research are no easier than other partnerships.
- Some collaboratives may be for life no just for ‘Christmas’
- Funder and policy environment clearly constrains what is possible.
- Collaboration with end user is however a core and enduring feature of much policy enhancement research.
- Emancipation—perhaps not, but working together in research more than a passing phenomenon
Thanks

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