GETTING THINGS CHANGED

Ideas Briefing 4

Disabled people have often had things done *for* them, in relationships where they have no power. How can we challenge this type of power imbalance?

Summary

- Disabled people are citizens[1], and this means that they have rights as well as choices and that they make contributions to society, as active agents in finding their own solutions.
- 'Bottom up' change is really important, because it challenges existing power structures in government.
- It also challenges the power structures at a local, micro level – where individuals may be treating disabled people with disrespect.
- The word 'co-production'[2] has only recently been applied to this type of activity, and implies that there is a jointness or collaboration in decision making. It also implies a type of equality.
- The rhetoric of co-production is easier to articulate than the reality[3].

1) Not all disabled people will want to take up active roles in co-production, in the same way as not all non-disabled people are active participants in civil or political society.
2) The solutions for one disabled person might be different from another, because the specifics of impairment do matter – therefore representation of one group by another can be contested.
3) Co-production requires a power shift in the way things are done.

- Understanding the principles of co-production can help us work out how to shift practices. Disabled people can challenge power imbalances and re-shape things to make them more equal.
- Analysing co-produced change is best done in a way that mirrors the topic, by co-produced research[4].

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[1] Article 29, UN Convention http://www.un.org/disabilities/convention/conventionfull.shtml

[2] Co-production: see Boyle, D., Slay, J. and Stephens, L. (2010) *Public Services Inside Out: putting co-production into practice.* London: HEF/NESTA

[3] Scourfield, P. (2015) Implementing Co-Production in Adult Social Care: an example of meta-governance failure? *Social Policy & Society* 14 (4): pp 541 – 554.

[4] Barnes, Colin (2003) 'What a Difference a Decade Makes: reflections on doing 'emancipatory' disability research', *Disability & Society, 18:1, 3 – 17*

What is the problem?

When a disabled person wants to do something, they may need more support to do it than a non-disabled person. So for instance a man with learning disabilities wants to go to the pub, but in order to go out and meet his friends, he has to make sure that he has a support worker to help him get there. The support worker then starts to tell him he should not get drunk, and to watch him so that he does not drink too much[5]. There is a differential in power and in authority between these two people, and the power of the service provider is often vested in their 'institutional' role. Of course, power can easily be abused, and that is what seemed to happen at Winterbourne View, where staff assumed they could apply brutal methods to 'control' residents, and the result was akin to torture[6]. In a broader sense, society and government operates as if disability were a problem, and so solutions are imposed on disabled people – this type of institutional power is often wrapped up in a benevolent guise, but can show its teeth at times of austerity during processes such as work capacity assessments, where disabled people have to 'perform' their disability in order to keep their benefits.

What is the policy?

UK social and health care policy have recognised since the 1970s that user participation can make a difference to public services; the concept of co-production now underpins person-centred care and personal budgets, at the level of the individual[7]. In health care, the Expert Patient programme introduced a model of patient participation in their own care[8] and this theme is now reflected in mechanisms such as Healthwatch introduced in 2012[9] and in co-production guides for instance with older people[10]. Similarly the statutory guidance for the 2014 Care Act defines and promotes co-production, introducing the concept into every part of the social care process. Practice examples of co-production include a project started in 2009, working with people with dementia living in residential care in Swansea, within a reciprocal model of shared living[11] and various other asset-based projects, where services are shaped by those who use them. Some local councils, such as Islington Council, have introduced co-production into their way of working, with a 'Framework for Involvement', intended to directly influence the commissioning cycle. [12] Since 2009[13] government ministers[14] in the UK speak the language of co-production, where those who use social and health care are able to be equal partners in their own services, and in framing policy and practice.

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[5] Example from training DVD co-produced with people with learning disabilities, available from val.williams@bristol.ac.uk

[6] Bubb, S. (2014) Winterbourne View – Time for Change. https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

[7] Department of Health (2006) Our Health, Our Care, Our Say

[8] Department of Health (2001) The Expert Patient Programme www.expertpatients.co.uk

[9] Health and Social Care Act 2012 c.7, Part 5 http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

[10] NDTI A Guide to Co-production with older people http://www.ndti.org.uk/publications/ndti-publications/department-of-healths-co-production-guide

[11] 'All Together Now' project http://www.scie.org.uk/publications/guides/guide51/practice-examples/all-together-now.asp

[12] http://www.scie.org.uk/publications/guides/guide51/practice-examples/islington.asp

[13] Needham, C. and Carr, S. (2009) Co-production: an emerging evidence base for adult social care transformation, Research briefing 31, London: Social Care Institute for Excellence.

[14] Minister for Disabled People (2011) https://www.gov.uk/government/speeches/co-production-working-with-disabled-people-from-the-outset

How can we look more closely at these issues?

Social movements of people who are oppressed provide us with theories of change; by taking collective action, people in Black Pride, feminist or gay movements have changed attitudes and law in their favour, challenging the power of the majority rule. We need to look towards ideas about agency, humanity and autonomy to understand how and why these movements can have an effect on social practices, policies and politics[15]. Disabled people have also developed their own collective voice[16], but there is a deeper disjunction for them between oppression and need. Since they are often in situations where a level of social or health support is needed, the power of the state is continually reasserted in their lives. Foucault's messages about governmentality[17] give us an insight into the structure of this power, and can also help us analyse critically what is happening in social practices where disabled people encounter authorities. However, we can also explore ideas about positive bottom-up change in an appreciative way, to understand better the deeper embedded changes to practices and structures that might happen as a result of disabled people's actions. This also requires a critical approach, to distinguish the rhetoric from real change, and an understanding of what elements in social practices might be changed in a deeper way by disabled people's actions (see Ideas Briefing 1). We want to find out more about what 'co-production' genuinely means, and how to recognize it when it happens.

What do we plan to do?

Across the five strands of our research, we will be looking at particular service structures and interactions with disabled people, who are for instance students or staff in universities, patients in hospitals, parents in contact with social services, living their life at home with support. In all these situations, power differentials can be challenged and solutions can emerge from genuine and equal dialogue through co-production. Thus for instance universities can be very 'powerful' institutions, but disabled people's own voice can start at least to challenge the terms of engagement, which may result in actual changes at a practical level to the way things are done. That has happened recently with changes to proposed car parking charges for disabled staff at our own university. In one strand of our research, led by DRUK, we will go further than this to seek out initiatives where disabled people want to make fundamental changes to commissioning processes of services, striking at social practices in a deeper way. We intend to apply a methodology which looks for the positives in systems, called 'appreciative inquiry' to find out how this makes a difference, observing and critically analyzing both the processes of change and the effect on commissioning practices and power structures in the 'institution'.

How will this research help to get things changed?

In carrying out this project, the research team is working with disabled people, and we want to understand how change can happen on their terms, and in such a way that their rights are enhanced (put ref in to 'on side' research). However, we do not want to fall into the surface-level trap of assuming that co-production always works. We are more interested in the deeper ways that social practices can be changed. We want to make sure we get to this level of analysis, and so we will for instance a) actively support user-driven commissioning, by facilitating the efforts and confidence of disabled people's organisations via a change development worker; b) support disabled students to

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[15] See for instance Amenta, E., Caren, N. et al. (2010) The Political Consequences of Social Movements. *Annual Review of Sociology,* 36: 287-307.

[16] Oliver, M. & Barnes, C. (2012) *The New Politics of Disablement.* Palgrave Macmillan.

[17] Lemke, T. (2012) *Foucault, Governmentality and Critique.* Taylor & Francis.

be co-researchers in changing the academy; c) develop creative strategies for young disabled people and those with dementia to guide and challenge the interactions that occur with support workers. All the strands of our research have strategies to ensure that we not only understand what is happening in organisations and in practices, but that we can use that understanding to make a difference through workshops, individual development sessions, or training. In developing positive change, we want to understand better the true nature of power, how it can be equalised and shared, and what co-production really means, so that these ideas can be replicated and can influence policy more widely.

Working to make links

- Understanding power from the bottom-up is key to all the strands, and we hope to offer new perspectives on how power is reproduced in micro ways (in interactions), and in institutions such as health or social services.
- Researcher positioning is key to the changes made through co-production, and we will explore the different ways this can happen across the strands of our research, feeding into theories about emancipatory change.
- Social practices are often assumed to belong to those with more power, such as institutional actors. We will make links with interventionist work around 'practice', offering a perspective on co-production of social practices from the bottom up.

Key questions

1. What is co-production and how do we recognise it when we see it?
2. What conditions and contexts help co-production to strike at a deeper level, in order to really make a change to the way things are done?
3. How can we understand the way power is embedded in institutional practices, and how can power be equalised at micro or macro level?