Reflecting on disability, personhood and personalization in a time of Big Society

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Big Society? Disabled People with learning disabilities and civil society

- [1] To identify, in the current climate, what opportunities exist for people with learning disabilities to contribute to and benefit from the Big Society and, hence, civil society;
- [2] To explore how disabled people with learning disabilities are participating in British civil society in the 21st Century;
- [3] To examine the ongoing and anticipated impacts of cuts in public funding and new policies of the coalition government on civil society organizations aligned to people with learning disabilities;
- [4] To consider to what extent three layers of Big Society (empowering communities, opening up public services, promoting social action) are illuminated by the practices of three civil society partners (circles of support, real employment, self-advocacy)?
- [5] To find out how people with learning disabilities are experiencing opportunities for (self)advocacy, employment and community support and participation in civil society?
- [6] To explore the extent to which these examples of civil society impact on the cultural capital and social and emotional well-being of people with learning disabilities.
Methods

- **Phase 1: Key stakeholder interviews:** interviews with disabled people with learning disabilities, members of the third sector, policy makers, lawyers

- **Phase 2: Longitudinal documentary analysis:** an extended analysis of academic and policy literature relating to Big Society.

- **Phase 3: Ethnographic case studies with co-researchers:** an extended period of ethnographic work with the three partner organizations: circles of support; self-advocacy; ‘real’ employment.

- **Phase 4: Analysis:** a period of analysis following the data collection in phases 1, 2 and 3.

- **Phase 5: Impact workshops:** a series of impact workshops to share our findings and develop analysis and impact.

- **Phase 6: Researcher in residence:** a researcher from the project will work with partner organizations to promote knowledge exchange.

- **Phase 7: Public Engagement Events:** a series of events to share research findings and increase the impact of the project.
We are all working together
Overview

• Bring together some contemporary examples of policy and practice in dialogue with debates within moral philosophy focused on the lives of people with learning disabilities

• Big Society

• Austerity
Policy Context 1: Big Society

- “You can call it liberalism. You can call it empowerment, you can call it freedom, you can call it responsibility. I call it the Big Society” (Prime Minister David Cameron: 19th July 2010 cited in McCabe, 2011:2).
Policy Context 2: Austerity

• austerity is characterized as a necessary period of ‘efficiency’ and ‘thrift’ in order for the state to recover from ‘financial crisis’ (Jensen, 2013).

• the removal of state support will 'toughen up' those who have become dependent upon it (Jensen, 2013).

• the austerity narrative is built on the language of emotion: ‘through envy, distrust, disgust and shame.’ (Jensen, 2013: 2)
Policy Context 3: Personalisation

• *Valuing People* (DoH, 2001)

• Person at the centre

• Choice & Control

• “Person centre approaches”
Recognising personhood

- Person centred plans = act of recognition

- Through this act of recognition is there simultaneously re-articulation of the view that people with LD have not, and might not, be seen as persons?

- Debates about personhood are potentially problematic
Berlant’s (2006: 21) describes cruel optimism as: “a relation of attachment to compromised conditions of possibility. What is cruel about these attachments, and not merely inconvenient or tragic, is that the subjects who have x in their lives might not well endure the loss of their object or scene of desire, even though its presence threatens their well-being ...”
The promise: active citizenship

- Valuing People (DoH, 2001)
- Improving the Life Chances of Disabled People (DoH, 2005)
- Valuing People Now (DoH, 2009)
- Death By Indifference (Mencap, 2007)
- Winterbourne View (DoH, 2012)
- The Connor Report (Hussain and Hyde-Bales 2014)
The ‘disability commons’

• Disablism is defined by Thomas (2007: 73), as ‘a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well being’.
Working the spaces of neoliberalism

- Three Vignettes
Vignette 1: Henry’s Circle of Support

Henry is an 18 year-old-young man with the label of learning disabilities. He is going through what is known as ‘transition’ in English education policy as he moves from children’s to adult services in education, health and social care. This is often a very fraught time for young people with learning disabilities and their families have to navigate complex service systems and negotiate new support packages (Goodley and Runswick-Cole, 2011). Henry’s family were struggling to find out what would be available for Henry when full time education finishes at the end of the year after his 18 birthday. Henry’s mum found out about circles of support and, working with a voluntary organisation who trains circles facilitators, Henry has been able to bring together a circle. Henry’s facilitator is paid; the facilitator’s flip charts are branded with the logo for the organisation she works for that supports and trains facilitators. The company is a thriving enterprise building its networks of circles in the north of England and beyond. Henry commissions the services.
Vignette 2: Chris’s job

Chris is in his thirties, he is married and lives with his wife. He works five days a week in the offices of a meals delivery and welfare service. He is out most nights involved in his local community; his favourite activities are the local theatre group and the local country dancing nights. Chris is a paid employee who contributes to his local community.
Vignette 3: Jodie, the 'expert by experience'

Jodie is an ‘expert by experience’ working for the Care Quality Commission. Several times a year she inspects services provided for people with learning disabilities. She has been involved in the assessment of the quality of the provision for a year. Jodie is an inspector.
Finally

• How do the debates about personhood operate in the lives of disabled people?
• What kinds of persons made and unmade within policy and practice?
• What impact does this have on the day-to-day lives of people with learning disabilities?
• Is it possible to escape the cruel optimism of a broken promise and to claim (normative) personhood in the lives of disabled people with learning disabilities while simultaneously acknowledging vulnerability as a condition of living?
#justiceforLB

http://sarasiobhan.wordpress.com/fundraising/
References

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