

Exploring the impact of welfare reform on the lives of disabled people, a qualitative study.

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Background

- The aim of this paper is to examine the impact of changes to disability benefits in the UK for disabled people.
- The changes followed on from the 2008 financial crash and encapsulated a range of reforms first initiated by the Labour government (2005-2010), fully realised under the Conservative and Liberal Democrat Coalition Government (2010-2015) and continued by the 2015 and 2017 Conservative administrations

Methods

- Funded by the Disability Benefits Consortium (DBC), a national coalition of over 80 charities.
- We interviewed 50 disabled people who had successfully been awarded funding following reassessment for PIP
- Respondents aged between 21 and 65 years (average age of 45) and included 25 men and 25 women.
- The study was advertised through Disabled People's Organisations, social media, and through the DBC partner networks.
- These interviews focused on participant's history of disability and benefits, their recent (3 years) experience of PIP, ESA and Universal Credit.

Analysis of interviews

- Thematic Analysis (Braun and Clarke, 2006) provided the framework for analysis.
- Analysis involved initial coding of interview transcripts, which was data driven rather than being led by pre-existing theory.
- Once the entire data set was coded, the research team searched for themes within and between codes.
- This process resulted in a thematic analytic framework, which was reviewed periodically within the research team.

Application, contesting and renegotiating selfhood

- *“In order for you to succeed with a PIP application, you have to appear to be completely dependent on somebody...for things like cooking and preparing drinks and managing day-to-day affairs. They somehow seem to think that the payment is not justified if somebody is disabled AND reasonably independent, which is such a pity because then they’re not really promoting independence. If you are disabled and you say you can cook and you can manage the house reasonably well on your own, then they would invariably say, “Well, you don’t need PIP” (Riya, female aged 45).*

Fluctuating conditions

- *“I found lots of questions very hard to answer because with ME you can do something once, but if they ask me to go again... half an our later, I wouldn't be able to do it because by that point I would be needing to be resting” (Ellie, female aged 55).*

Wellbeing

- **Lucy, female aged 52 with rheumatoid arthritis**
- *“I think the whole process from filling in the form and waiting for the assessment to come and it was like this looming thing hanging over you and then the assessment happened and it was... It kind of felt hard to get through and difficult and quite emotional and you can't get out and then you had the stress of worrying what's going to come of it and how they see you”.*

- **Amber, woman aged 37 with chronic pain, diabetes, mental ill-health and wheelchair user**
- *‘A friend was bringing my daughter home at one point she just said, “Mummy when every day I come home from school, you’re on the phone crying”. And I was like, every day, I would start ringing at 11.00 and when she got home at 3.30 I was still on the phone.’*

The hard work of collecting and presenting evidence

- *'I don't [see healthcare professionals] ...unfortunately, my condition is not medically treatable. So, whilst I have a letter of diagnosis from a consultant, there's no current treatment, so I don't see the medics for my disability. I asked my nurse practitioner to write a note because she was actually the one that I've seen most recently and most regularly and has any degree of insight with regards to my disability'.*

- ‘The assumption is disability equals ill health and constantly being in touch with medical professionals, naïvely assuming there is a constant paper trail. Which is often not the case’’. Felix, 27 year old CP

Support

- **William, male aged 27 with cystic fibrosis**
- *‘Without the support of my mum, I think it would have been very difficult. It’s something I’ve thought about afterwards – when you’ve got to collect this evidence...I don’t think I’d have gotten as far as I did; my confidence isn’t 100% with that sort of thing so I think trying to keep on top of my health as well would have been very difficult’.*

The financial impact of the changes – independent lives?

- *'We're struggling. Massively. Massively struggling. Massively. My husband gets his state pension at the end of September, but we have to survive until then; we are massively struggling...It really isn't sustainable. [When I lost the higher rates of PIP] it cost us £600+ in lost benefits plus it means that I feel as though perhaps they think I've lied all the time...I know I have these problems but the DWP don't seem to think I do'.*

- *“I wake up in the morning and I’ve got no gas, no electric, no food and it just upsets me that I’ve got no food to cook. It’s not a life that you’d want to wake up to and think, have I got to live the next 40 years of my life like this? You can’t depend on the benefits system because they don’t give you enough money to live off. You’re constantly going to be struggling with debt and finance, for the rest of your life; if my life is going to be like this for the rest of it I don’t want to be here. I would rather commit suicide than live like this, it’s not a life”.*

Questions

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