

ORAL HISTORY EXTRACT TRANSCRIPT

'Fighting for our Rights' project

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Extract 1: flexible approach to care for disabled parents

I think it was 1996 when I started receiving direct payments, and in those days KCIL was providing the money as well as the paperwork. I don't remember a huge amount about it, except that the flexibility allowed me and my PA to work quite creatively. My PA at that time was a middle aged woman, a married woman, who lived in North Kingston, and what became totally apparent was that if she tried to get Jonathan, my younger son, to do something and he knew I was around, he would not cooperate. So we cooked up this scheme whereby whatever night it was in the week that she bathed him, she would actually do that at her house rather than at my house, and that worked really well. Her husband was really supportive. So they would keep him for the night and she would deliver him to school in the morning. And I think it happened for a shortish period but it worked very successfully, and that's not something you can do if you're receiving traditional services. I particularly remember that, because although Jonathan, my younger son, didn't have any diagnosed impairments, he was a major handful. By the time he was nursery school age. and infant school aged he was a major handful. So we had to do things flexibly to get the best outcome. If he wasn't in my house and I wasn't around he would be delightfully compliant. And that's why I felt that a lot of what was being offered to parents in terms of support-- , well, to disabled parents in terms of support for their parenting role, needed to be a little bit more realistic about what actually does work and some of the things that don't work for certain children and their parents. So that did give me a particular interest in the nature of the support that adult services can provide for disabled parents.

was a lifesaver. It was a lifesaver because, as I said, we could work it out in a way that worked for us. At the time, and possibly even nowadays (I'm not involved in that policy area any more), the big drawback of support for disabled parents was this idea that the child, the parent and the PA all had to be there at the same time, because that dynamic doesn't work for a lot of children. If the mother's there they're going to play up. They don't want the PA to do it. They want the mother to do it. So there are practical implications for the way support for disabled parents is provided.

Extract 2: campaigning and the 20 metre rule

After the coalition government came into office in 2010, I did a lot of campaigning, mainly on welfare, especially the replacement of Disability Living Allowance with Personal Independence Payment for working aged disabled people. I even got known at one point as "Mrs 20 Metres", because of the PIP requirement that in order to get the enhanced rate of the mobility component on the basis of walking difficulties you've got to be able to walk less than 20 metres. So I wrote articles for the Guardian and was interviewed by television channels a couple of times. The way that I and a few likeminded campaigners worked was not the kind of DPAC (Disabled People Against Cuts) method of going and sitting in your wheelchair in the middle of the road near Parliament, but by researching and writing accurate, well-written reports, in terms of like producing a cogent argument for something different from what the government was planning to do. But it was a fairly thankless

task because they didn't listen to any of it. It does feel good but they didn't listen to any of it. What was really interesting though was I also worked with some lawyers to take some judicial review cases on some of the specific aspects of the changes. We did it on what's been commonly known as the bedroom tax, in terms of the impact of that on disabled people, and we did it on the PIP 20 metres issue. One of the bedroom tax cases was ultimately successful in the Court of Appeal a few weeks ago, but the PIP case wasn't successful. We did force the government to do another consultation on the 20 metre criteria, though; they didn't listen to the responses to that either, but we tried. So that was very different for me. Campaigning was something I had done before, especially in relation to disabled parenting, but not in the way that I was doing then. Writing for the newspaper and being interviewed for the television were definitely things I hadn't done before.

Extract 3: positive reflection on innovation in Kingston

As you'll have heard, I've done a lot of work around disability and various aspects of social security, social care, independent living, etc, over many years. None of that would have happened if I hadn't started my life as a disabled person in a borough where independent living was understood at that time as an important concept, a borough full of disabled people who have been in the vanguard of persuading local authorities to completely change the way they provide support. That feels a fitting way to end my contribution to a project that is all about those people and how disability in the borough of Kingston has been an important and... meaningful issue for the borough as a whole, going back firstly to the disabled people who started it all off but also the managers they spoke to at that time, who were willing to do something different, to spend public money in a different way, to change the way disabled people receive support and therefore free a lot of disabled people to just live their lives rather than worrying about their support all the time.