

ORAL HISTORY EXTRACT TRANSCRIPT

'Fighting for our Rights' project

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Given name(s)	Kay
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Extract 1: support from parents

And the doctor there told her straight away that I've got cerebral palsy. Of course Mum didn't know what it was at that time, and she was shocked because--, she hadn't married my dad by then, the dad I've got now, but in the months that--, during that time she met my dad and they got married. I was about two and a half by then, and they got married, and Mum said they told her then, "Don't keep her. Put her in a home. She's never going to amount to anything. She's going to be a cabbage or suchlike." And my mum said, "No way in this world is my daughter going to be a cabbage. I'm going to treat her and look after her." And she did, taught me to read, write. I was reading the News of the World at five years old, so that's how good my education was at home. Without my mum I wouldn't be as good as I am today really, I suppose, you know. But they were good parents, and my father brought me up well, and after Brenda was born my mum used to give me exercises. They had one of these dining room tables that you pull the leaves out, and she used to make me--, got mats to put on the table. Every day I exercised and Mum went, "You're going to walk. You're going to walk." And I did. So she was brilliant. My dad used to help me, take me up the hospital every day to make sure I had the treatment I needed.

Extract 2: joining independent living scheme

Yes, that's when I met Ann McFarlane. I was over at this--, Surbiton health centre, which it is now, used to be a hospital, and it had x-ray places then, and I had to go for an x-ray. And I'd had to get the morning off work to go, and then I thought, how am I going to get to work after that, I'm going to be late, oh no. And I'm sitting there and I must have looked really down because Ann McFarlane came over and said, "Whatever's wrong, Kay? You look so distressed." I said, "I'm just fed up, Ann, fed up to the teeth." She said, "Why?" I said, "You know, I don't have help." I said, "I'm always late." And I said, "And then the taxi's always late, and I'm losing money at work. I'm working like a trooper, but," I said, "I'm not getting anywhere. I'm late and they take the money off me because I'm late, which they've got a right to do in a way. They're not in there for--, it's not a day centre." So she said, "Let me think about it, Kay." Then she must have gone and done what she had to do at the hospital, and I'd come out as well and I was just going home, she said, "Kay, hang on a moment." So I said, "What's up?" She said, "Me and some friends are starting up a scheme to get our own staff." And at that time it was called--, it wasn't called a personal budget then. But she said, "Why don't you join us?" I said, "What does it entail? Does it need money, because I haven't got none?" [Laughs] "No, no, just come down and see what we've got to say," which I did, and then there was five or six of us then. Yeah, it's a great idea, I like that, you advertise for staff to come. If they get on with you, you do what you have to do. And then I was a lot better than I am now. I could still walk. Although I used a chair

outside on the street, I could still walk around the house and so forth. So yes, and when I see what happened, it's been the change in my life, I tell you, the best thing that's ever happened to me really in a way, because it--, well, rather than--, I can have who I want to work for me or not have someone I don't want work for me, and they can come when I want them to be there. And that helped. I never was late for work after that, because I could say, "Look, I need you to an hour earlier than--, because I've got to get there as well," and they did. That was--, I'm trying to think--, I've been on the scheme from the very beginning, so it must have been more than 25 years, I'm sure.

Extract 3: to live not just exist

It's reasonable, I manage, but I've had to fight for what I want, with the help of a friend. I don't think the council realise how much disabled people need certain things. You know, my shoes, when I was walking, I got through a pair of shoes a week. I had to buy new shoes every week because I'd wear them out, the way I walked. And if you're disabled and you need incontinence things or certain medicines, you've still got to pay for them. You don't get them all free. Dentist, you know, I've to pay. It's hard. And when I do try to get a bit more, you know, they just don't really understand. Always complaining about money for disabled people. We're not asking for the crown jewels. We just want to be able to live as normal as everybody else does, as best as everybody else does, to be able to live and not just exist. It's alright existing if you're-, but people who've got good mental ability, they want to be able to live, not just exist. I think that's what's wrong with it all, you know. I want to be able to go out and enjoy myself like anybody else does, and I can't go on my own. I've got to have a carer with me, and of course they've got to be paid. They don't understand that kind of thing. I can't go anywhere without a PA