

ORAL HISTORY EXTRACT TRANSCRIPT

'Fighting for our Rights' project

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Extract 1: Andrew's development

And looking back I realise Andrew was a total square peg in a round hole because Andrew has always been, I will do it my own way. So to try and get Andrew drilled into doing a specific way, they were trying to get him to get to a sitting position when he could already sit on the floor if you put him, and keep his balance. And he had developed a way that he could roll over, get onto his knees and get into a vertical, well a sitting position. So they were trying to teach him how to sit properly and one day I said, "Are you aware he can actually sit? Are you aware he can get himself up?" And they said, "No. How can he do that?" I said, "Okay, well give him a chance and let him show you." So I said, "Okay Andrew, get yourself sitting." So he did, and they were absolutely gobsmacked. So they were trying to go through everything he innately had already been teaching himself to do. Actually he was one years old and we were on the beach in South Wales when he first sat for a long time unsupported on the beach. And I actually said, "I'd better take a photograph of this. I didn't know he could do this." But of course the sand was moulded around his body. And it took about another three months before he could sit on a hard floor. But he would literally look around the beach, and he would look at what other people were doing and then he would model his behaviour on what he was observing. And to actually watch this thought process going on was really quite startling 'cause you could literally see it going in and think, right I'm going to do that. And so he just didn't fit in with this very rigid regime at the Spastic Centre.

Extract 2: working with Kath Turner and funding for Andrew

She was brilliant, she said, "Look there will be a care, it won't happen immediately, but you will get funding to help with the care for Andrew. So there will be light at the end of the tunnel. So it must feel awful right now, and I'm really sorry I can't say it will happen immediately, but." The following day she rang up and she said, "I don't believe it, but I've got you funding." So she was brilliant. She said, "But actually I think what we need to do is assess him for the government funding as well called Independent Living Fund." So she said, "Please will you write a day in the life of Andrew?" And she said, "And make it as bleak as you can. Don't cover over any of it, this is your worst case scenario for a day." So I wrote it, and sure enough he got Independent Living Fund. To get Independent Living Fund at Andrew's stage you had to have funding from the local authority. There had been a slightly earlier stage, and there were one or two people in Kingston who hit it at the earlier stage, who got 100 percent ILF funding, the national one. To make things really complicated, Kingston in their wisdom decided to call their scheme ILS. So you had ILF and ILS, two different pots of money. Two different assessments going on. You had to have this to be able to have this. You also had to be on Income Support. We had no idea Andrew would be eligible for Income Support. You know we assumed everything would be means tested on us. And Kath was actually absolutely brilliant in saying, "No he's got rights of his own. He's a young man and under normal circumstances what would he be doing?" And I said, "Well he'd be at university." She said, "Precisely, he'd be leading a

totally independent life, and he has a right to that.” So really it was Kath Turner who gave us that. And Kath was absolutely wonderful.

Extract 3: Ongoing battle of receiving care

With Andrew, with the lack of communication he and I have a terrific understanding between us. It is very, very draining. And trying to be on his wavelength the whole time is really difficult. He has a very clever way of putting words together, but sometimes if you're not on the right wavelength you don't totally understand and there can be fireworks. So you've got to be 100 percent alert. If you go to the GP the GP will usually say, “Well what do you think is wrong?” And the responsibility and the onus is really quite considerable and great. But I've got every sympathy with them because the level of communication is really, really difficult, and I'll say, “Well one of the reasons I've come here is to ensure I'm not missing something, and I really need you to look at it.” Once a person is 18 there is no ongoing medical specialist advice, especially for something like cerebral palsy. There might be for some other conditions, but we've had no professional overseeing Andrew. And in fairness to the social worker who took over from Kath, she was the first person who said you can have a wheelchair assessment. So in fairness some good came out of it. And the wheelchair people have been absolutely brilliant. But now they are saying they're really worried 'cause Andrew's head is down on his chest, and it is likely to get further down so it's going to cause more breathing and eating difficulties. And we've been watching it visibly deteriorate, even since they pointed it out. But about a year ago I asked the GP for a referral for physio, and the physio wrote back saying because it is not a skeletal problem we cannot give physio. If you can explain to me how spondylitis, head coming down to your chest, foot going over so the bone joints are being really quite badly damaged is not skeletal in any way, I would be very grateful. But if Andrew had had on going physio I think a lot of these problems would have been pre-empted. The hamstrings behind his legs are so tense and tight he really can't straighten his legs. So even at night time they have to be bent. It's an ongoing battle. He's recently complained of toothache, so we've had to have a new referral back to Guys Hospital. And we're still waiting for that to happen. Everything is just one on going fight.