

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Young
Given names	Jane Sarah
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Q: This is an oral history interview with Jane Young by Jen Kavanagh on Wednesday 7th June 2017. The interview is taking place at Jane's home in Kent as part of Kingston Centre for Independent Living's Fighting for Our Rights project. So thank you very much, Jane, for being interviewed for this project. Could we start with you stating your full name, please?

A: Jane Sarah Young.

Q: And what is your date of birth?

A: [REMOVED] 1960.

Q: And whereabouts were you born?

A: Twickenham in South West London.

Q: And what were your parents' names, or are your parents' names?

A: My late father was Paul Hindle and my mother, who lives in the Kingston borough, who has Alzheimer's, her name is Cicily Hindle.

Q: And what were their professions?

A: My father was a businessman and my mother was a history teacher.

Q: And whereabouts did you go to school?

A: Until I was about 12 or 13 I went to Lady Eleanor Hollis School in Hampton, and then when we moved up to Norwich to be near my mother's family, I went to Norwich High School, both just girls' schools, independent schools.

Q: And what was your education experience like?

A: Well, at the rather high performing girls' schools that I went to, it was quite sheltered. I was obviously given a good grounding, but when I went from school to university I didn't really have any idea of what I wanted to do longer term.

Q: So what did you study at university?

A: Well, I went to university to study chemistry, but after about five weeks I realised that I really didn't like it, so I went over to the law faculty and talked to them and they said, "You can start next year so long as you finish this year doing chemistry." I think they wanted to make sure I was able to stick at something I didn't want to do. So then I ended up at university for an extra year because I started a three year law degree course the following year. So one year chemistry and then three years' law.

Q: Did you enjoy law more?

A: I did enjoy law. It was at Southampton University. I got a 2:1, which I was very surprised about because the paper on tax law was horrific. But I wasn't sure whether I wanted to practice law, so after university, on the basis that I didn't really know what I wanted to do, I did a short postgraduate secretarial course at the then City of London Polytechnic.

Q: And then what was the first job you had once you qualified?

A: [Laughs] My first job was a kind of girl Friday job for a publishing firm. I think my salary was £4,500 a year, something like that. It was very low even by the standards in those days. So that was--, that must have been 1982--, no, 1983, I think I must have started there. That was my first job. I didn't stay very long because the company moved somewhere where I didn't want to go to. Then I--, what did I do after that? I went to work as a secretary for a solicitors' firm, and then after that I went and worked at the Royal College of Midwives, firstly as meetings secretary and then as the PA to the boss, the general secretary, who is still a friend to this day. And when I got married I had a couple of other secretarial jobs and had my first child in 1989. So David is now 28 and he's married, and I didn't go back to work. Jonathan was born in 1992. They both live in New Malden still in the Kingston borough. And I--, so I didn't go back to work until I think Jonathan was three, but by that time I had already become disabled, so life was getting a little bit more complicated.

Q: Could you explain what the nature of your disability is?

A: I have ankylosing spondylitis and quite a bit of osteoarthritis in my spine. We went over to the States for six months in 1994 and the problems started then, but I didn't get a proper referral and diagnosis until we came back. So diagnosed maybe 1995. It's progressive, so there have been times when I've been really stable and times when I've got quite a lot worse quite quickly, so that was--, that's what happened anyway.

Q: How does it present itself when it's particularly bad?

A: Well, at the moment I'm stable, so mainly it's a painful condition. So I've been on morphine for quite a while, and it might not be the greatest thing but I'm stable and reasonably functional. My mobility though has been poor since about '95 and I started using a powered wheelchair in about 2004, I think. So yes, the other thing that happened, ooh, maybe--, must have been 2008, 2009 was my ribcage expansion deteriorated and breathing was painful, and it was at that point that my GP suggested that maybe I should not still be working, which horrified me a bit because that's what you do, you work. What else do you do? So that's kind of--, yeah, that's the progression, very briefly.

Q: So when you were first diagnosed, what services were you aware of or what services did you access?

A: There was a bit of difficulty. When I was diagnosed my children were five and two, I think, and my older son has Asperger's. He's on the autistic spectrum, so he was a challenge because he's what you might call a runner. He didn't really want to--, he didn't really realise why he needed to be near me so he'd just run, and I couldn't run after him, so that was a problem. I asked the health visitor if I could get any support. She asked children's social services, who said no. I then started going to a drop-in centre, which has long since closed, the Willow, and one of the people who worked there in early years, she had a better understanding of services, and she said, "Well, you need to phone a disability team." So I phoned the disability team and the first person who got back to me was Phil Levick, who clearly had a big role in the Independent Living scheme in the early days, so that was that coincidence. Then what happened was, because I primarily needed support with parenting, the disability team and the children and families service did a joint assessment and I think the disability team funded services from the children and families service around some nursery provision for my younger son and playgroup provision, etc, so that we kind of had the week covered. By that time my older son was at school fulltime so it wasn't such a big deal.

Q: So was it Phil that made you aware of the Independent Living scheme?

A: No, I don't think it was, because to start with I had this package that was in the main delivered by children's services, and it was one of the people who supported me through that source who alerted me to the Independent Living scheme, because she also worked for another disabled parent. And I seem to recall that's how I managed to move from having this jointly commissioned service to direct payments. I'm a little bit hazy about what happened when, but I think when the direct funding of support from children's services had finished, the way was clear for me to have direct payments so that I could employ my own PA to help me parenting my boys. I think that's what happened. So it was a bit of a roundabout route.

Q: Thanks. So how--, in terms of then receiving those direct payments, can you talk me through how that works from your perspective, if you don't mind? [Laughs]

A: Hmm, it's a very long time ago. 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 to be honest, except that the flexibility allowed me and my PA to work quite creatively. So my PA at that time was a middle aged woman, 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 just 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 aged and infant school aged he was a major handful, so we had to do things flexibly to get the best outcome, because if he wasn't in my house and I wasn't there 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 some 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.

Q: What impact would you say receiving direct payments had on you at that particular time, on your life?

A: It was a lifesaver. It was a lifesaver because, as I said, we could work it out in a way that worked for us. Because at the time, and possibly even these days, I'm not involved in that policy area any more, but 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 PAs to do it. They want the mother to do it. So there are practical implications of the way support for disabled parents is provided.

Q: So it sounds as though, from your experience of that and very much encountering that firsthand, it got you involved with a lot of work then within the community. So how did you then come to be involved with the disability equality policy consultation that was taking place?

A: Phil Levick sent a letter out to I think all service users, saying that--, well, inviting us to a meeting to talk about a disability equality policy and I thought, ooh, this looks interesting, so I went. It was ambitious, mainly because I think it was one of the first times that community care services, as adult social care was called in those days, had tried to make a difference to services provided by other parts of the council. So the policy covered a number of areas in terms of the council services and needed buy in from the different directorates and departments. I remember at the time thinking, actually it isn't really right that community care services has to try to persuade other departments to make things accessible for disabled people, but back then, in the late '90s, that's where we were in terms of disability equality. So that's--, I simply got involved with that because I responded positively to a letter that was sent to service users. The rest, as they say, is history, I think.

Q: So what did that consultation involve from your perspective?

A: Well, Phil had managed to get representatives from various council departments to attend the meeting, and after the meeting I got involved in the group that was set up to monitor how things were going in terms of what had been agreed at the meeting, because you can't just have a meeting and produce a document and then do nothing because probably the answer is nothing will happen. So I got involved in what was then called the disability equality policy monitoring and review group, or something even longer winded I think it was. I don't even remember. But yes, we had periodic meetings with departmental representatives, service users and originally at least, elected members. Those were the people who were supposed to be involved with the meetings.

Q: How successful do you feel it all was?

A: It was the precursor to a number of initiatives really, thinking back. One of the initiatives that arose out of it, again at Phil Levick's instigation largely, was a group looking at what the council's policy should be on support for disabled parents. Nationally at that time that was a poorly understood area, and Kingston was quite proactive and a bit ahead of the game in terms of looking at it, because I believe from inspection reports that a number of councils didn't really even realise that disabled parents should have support funded by adult services, and a lot of parents were and still are really frightened that if the council got involved their children would be taken away. That's a common fear for all sorts of good reasons. So yeah, we set up this separate group and we ended up looking at some areas where it was quite difficult to make a difference, in particular what schools could or should do to include disabled parents and to make life easier. One of the issues that a number of the parents had was how to get their children to school, especially if they didn't drive, and I don't think that policy area has been resolved to this day to be honest. It's still a really difficult area, causes people a lot of problems. But there were other issues, like parents who couldn't tell whether the piece of paper in their child's bag was a picture they'd drawn or a letter from the school because they simply couldn't see what was on it. So we did get quite involved in trying to work out how school governors and heads could get better informed about the needs of parents. And well, yeah, that's the bit that I remember best. But I also remember being quite exercised over the fact that the policy needed to reflect reality, such as what I said earlier about having a service that insists that the parent, the child and the PA are all doing stuff together is not necessarily a service that's going to work the best in

terms of supporting the family. So I was chair of the--, well, I don't like the name but everybody decided to call it the Disabled Parents Action Force, and I was the chair of it, and it was my job to feed back from that to the disability equality policy group and for that group then to feed on into what was in those days quite an influential council committee, the policy and resources committee. So our concerns were fed back to elected members via a more formal route, as well as to council officers in terms of what changes they might be able to make operationally to different council services.

Q: Who else was a member of that group at the time you were chairing?

A: Ooh crumbs... There was a lady with multiple health conditions, who was quite--, she had quite a number of seizures, and one of her concerns was that her young daughter, who's the same age as my older son, David, was having to kind of take charge sort of at the age of about six or seven when her mother had a seizure. There was a woman who is blind, who has since worked for KCIL and has now moved on, whose children were small, and she was the one having difficulty working out what it was the school was sending home in the child's bag. There was a woman with MS who had one child. They're the ones I remember. I couldn't even tell you everybody's names actually. But yes, again it's a long time ago.

Q: And what do you feel was achieved during that period? What do you feel your main accomplishments were?

A: Well, with the main group, the disability equality policy group, we did manage to broker some links between the council tax department, whose missives go to every householder, and the sensory impairment team, trying to get some slightly more automatic way of council tax payers receiving information in a way that they could access it, so on CD or by email or some kind of accessible way. That was one thing, and I'm not sure how well that lasted into the future. But another thing I think was coming out with similar issues about visually impaired people not getting information in the right format, deaf people not being able to access meetings, etc. The interpreting service was set up at around that time, or fairly shortly afterwards, and I think it was that service that then was responsible for things like producing information on tape as well as translating into community languages, translating into British sign language, etc, and that became I think a corporate service across the council. In terms of the Disabled Parents Action Force, we did produce a policy that was I think adopted by community care services. We also became a bit known outside of Kingston. I remember Phil and I going up to a meeting about support for disabled parents over at Radar, which--, longstanding organisation, has more recently been incorporated into Disability Rights UK, because they were doing some work on it at Radar. And I remember some researchers coming to do interviews of disabled parents in Kingston because they had heard that we were quite kind of ahead of the game in this area. And then quite a bit later on, I think it was about 2005, Phil Levick and Sheila Hart, who was at that time the manager of the health and disability team, and I all went up to Market Harborough in my car and spoke at a--, I think it was East of England social workers' conference or something like that. So we did get a bit known for that, and I do think that we improved the situation for disabled parents needing support in the future. We especially tried to make sure that health visitors and children's services knew the answer if the disabled person went asking for help rather than not knowing the answer. So yeah, we did achieve, we did achieve some things, yeah.

Q: Were you providing training in terms of, like you say, ensuring that people felt more confident with how to communicate?

A: Later on, in around 2006 or 2007, Phil and I got involved with some training of local authority and health staff in applying the disabled parents' policy. We did do that. I don't recall getting involved at that time in any training immediately arising out of the disability equality policy and that group, although I did do quite a bit of training later on when I worked for Kingston.

Q: So can you tell me how you went from chairing that group and being involved with that consultation through to then becoming the access officer at Kingston Council?

A: Yes. Just before I took that post, I was chair of the action force and I was also chair of the disability equality group. I shortened its name. When I became chair I shortened the name. It was just getting too much. So when I was appointed I was chair of both, so at that point I had to relinquish the chair of both. I was working for a Christian disability charity down in Epsom, and one of the things that the disability equality group did was push hard for Kingston to create the post of access officer and approve the advert and so on. That's what we did as a group. The first recruitment attempt was abortive. The second recruitment attempt, I thought, hmm, maybe I'd like that job, so I applied the second time around and was interviewed by the building control manager and the guy in building control who had been fulfilling the access brief as far as he could up until that point. And I was appointed in 2003. So I was the first person in that post and that post unfortunately was deleted when I left, which was very disappointing. But yes, I had a whale of a time as access officer. That was an 18 hour a week post originally and then in 2005 I was appointed to be access officer at Hammersmith and Fulham Council-- sorry, I was offered the job--, I beg your pardon--, I was offered the job of access officer at Hammersmith and Fulham Council, and it was considerably more money than I'd ever dreamed of being able to earn before actually, to be fair. But the trek from New Malden to Hammersmith and Fulham, over Hammersmith Bridge, was just something I could not really--, I just didn't want to do it. So I went to Kingston and I said, "I'm sorry guys. I need to go, but I really want to stay here." I think by that time I had started to get involved with some of the equalities work that was led by the HR department. So I went to the head of HR and I said, "I can't afford to live on what Kingston's paying me. I've been offered this job but I don't want to go. Can you help?" And I was given another 12 hours a week as a result of that request. The other 12 hours a week was to work for the HR department as the disability equality lead. So I then became disability equality and access officer. That was my title from 2005. And I say I had a whale of a time because my main boss, as it were, the building control manager, Chris Island, was a very empowering manager, and very willing to trust me to use my own judgement in terms of what I got involved with. I used, as an abbreviated job description, my role is to improve the lives of disabled people in Kingston, really, really broad. He was fine with that. And at the time that I started at Kingston in 2003, they were in the process of preparing for the part of the Disability Discrimination Act which was brought into force in 2004, which was that not only did services and practices and so on need to be made accessible but buildings needed to be too. So at that time the council had a considerably large estate of buildings. I think it was something like 57 buildings or something. It's not nearly that much now because they divested themselves of a number of buildings when they needed to shrink and reduce expenditure. So I ended up acting as consultant to most of the government departments, working with them on their projects to improve the accessibility of the buildings that were accessed by the public. So that was one of the reasons it was great fun, because I worked with a lot of different people. The education department really needed my expertise, partly for that reason, partly because they needed somebody who could advise schools, but also partly because during that period inclusion in mainstream was really becoming a high priority, so we had quite severely disabled pupils wanting and needing to go to mainstream schools and needing to have the facilities. There was also the Building Schools for the Future programme under the Labour government. That meant we were rebuilding or substantially rebuilding a couple of schools, and so I was very much involved with that. But the bread and butter of my access work really was checking planning applications, initially checking planning applications for non domestic commercial premises, but then towards the end of my time at Kingston I did quite a lot of work on trying to get Kingston's new housing stock meeting higher accessibility standards. The London Plan had been published in 2004 and all new homes were supposed to comply with at least lifetime home standard, and ten percent were supposed to comply with wheelchair accessibility standard. I tried to introduce under the London Plan--, the policy was already out there but I tried to persuade developers to think of that not only in terms of social housing but also in terms of private market housing. I did--, on that topic and on other topics, I did quite a lot of cross-departmental work, so working with officers in other departments where that was necessary. Housing was an obvious one. There was the occupational therapists who were trying to place clients in new social housing. There was the housing allocations team, there was the housing development team. So housing was an obvious one. Occupational therapists were an obvious one, and all of the managers who had responsibility for public facing roles on the basis that what we really needed to achieve was all council services taking account of the needs of disabled people accessing those services.

Some of that was really uphill work. Different managers had different levels of understanding and sympathy with the agenda. But there was also things like the equality standard for local government, was a hugely process driven thing which I had a lot of responsibility for, especially when the equalities officer left and was not replaced and 12 hours a week I was supposed to be the equalities officer. It was really hard work. So that's why that job that I did from 2003 till 2008/09 was great fun. I did training. I produced mini training slots of 20 minutes long that I could deliver as part of section meetings or team meetings, partly on access, as in physical access, and partly more on disability equality and inclusion. I also worked with the primary care trust and the hospital trust. A couple of people you might have already interviewed, Ann Macfarlane and Pat Page were instrumental in encouraging me to work in partnership with health, because after the Disability Discrimination Act of '95 we then had the 2005 act, which necessitated the production of disability equality policies-- I beg your pardon, no--, disability equality scheme, produced by each government department or public sector organisation. So the hospital trust, the primary care trust, Kingston Council, everybody had to produce a disability equality scheme, and so when I ran the consultation events to inform the council scheme, I ran them in partnership with the primary care trust and the hospital trust so we could all benefit from what the disabled people were telling us about the problems they had accessing services and what they really wanted to see from local public sector service providers. So loads of work, loads of fun basically.

Q: The work that you were doing specifically for the HR department, what did that entail?

A: Well, mainly that was the equality standard for local government. So every service was supposed to have an equality impact assessment, not just disability equality but equality in the round. So for example, waste and recycling collection is a major policy area, a major service area for any council. I helped them to produce their equality impact assessment by encouraging them to involve disabled people and meeting focus groups so that their assessment was based on more than just what they thought people would need, more on what real people did need, and the impact of some of the aspects of the service on, well, minorities, disabled people, people from black and ethnic minority backgrounds, all kinds of people. So, you know, we even sort of discussed things like what we needed to translate into Korean, because Kingston borough has a huge population of Koreans. So yes, that was very varied, it was very different. I always found it quite difficult-- I had no training in equalities beyond disability equality, so it was quite difficult for me to cover the broader equality brief, but there was an equality officer in community services and he was a huge help. I was the only corporate such officer. So yeah, we... The equality standard for local government was very process driven, very paperwork driven. I don't think they have it any more, and that would be good if they don't. But making sure that every service was assessed for its impact on minority groups was a key part of the equality standard for local government, and I insisted that I was involved in those services that were really important and high profile, waste and recycling collection being probably the most important and high profile. Most people think all their council tax is paid for is to get their waste taken away, so very, very useful. I also insisted that when we did training we involved as much as possible disabled people themselves to explain quite simply what their difficulties were accessing various services. So that's why I remember it as being great fun as well as hard work. No day was ever the same. I used to get requests for advice from all sorts of people. It was a very, very varied job. I could have had twice as much time to do it and I still wouldn't have done it properly, I don't think, but I gave it my best shot.

Q: It's a slight aside but what were your thoughts at that time about how-- I suppose how far the council were in terms of employment of disabled people? Did you feel that measures were put in place to be able to do their job?

A: I did also get involved, you reminded me now, with supporting the occupational health department on some cases, because disabled employees who couldn't manage with the adjustments that the council had put into place, generally the occupational health department had to get involved because wherever possible we needed to put those adjustments into place so that staff could stay in post. My experience of the HR department, who were the department with the responsibility for equality policy across the board, was that they weren't too bad at employment related issues, but because they were an HR department

found it very difficult to relate to these service provision issues that are also part of the equality obligations for local government. Having said that, there were certain issues that--, where we really did not see eye to eye. One of those issues I recall was that I believe it's best practice for disability related absence to be recorded separately, independently of sickness absence, and that was a very tricky one. The occupational health department was rather health focused, as you would expect and wish, but found the equality and inclusion aspects a little bit more alien. So I felt a little bit like glue when I was working for the council, because I seemed to spend my whole time trying to stick people together, to help people make connections that would be of benefit, whether that was staff with internal services or whether it was service users for the right council service. I very much ended up doing that a lot. Disabled employees and disabled services users, and I don't just mean adult social care but residents basically, would often come to me because they really didn't know where else to go, so I did try to do quite a lot of bridge building between individuals and departments. So that was reasonably successful. Some of that was spectacularly unsuccessful. But I think the council was kind of average probably in terms of its employment policies for disabled people, not brilliant but not awful. There were a number of disabled staff who had got adjustments, and the occupational health department was actually very good at putting people in touch with Access to Work, the Department for Work and Pensions programme, to arrange support, mainly equipment, but that didn't really work once employees had been there for some years. So it was a tricky area, mainly where an employee had a more unusual condition or more unusual needs. Some we managed to make it work and some we didn't.

Q: So when did your time at the council come to an end and why did you end up leaving?

A: Right. Well, in 2007, some time in 2007 I went off sick for pain, disability related reasons, and I had a phased return to work once I'd been off two weeks. And at the same time we reduced my hours back down from 30 to 24 a week and spent a number of weeks and months trying to find ways of enabling me to continue in the job whilst needing a huge amount of flexibility, etc. But it was when I was driven home sick from work in the August of 2008 because I couldn't breathe that my GP started to have the conversation with me about, "Do you think you should really still be working?" And from then until April 2009 was the long process it takes from that point to when you have the arrangements made to retire on medical grounds. And through that time I was still doing some work at home. I had particular concerns about certain housing projects that I felt I needed to carry on to try and see through, and one of the senior occupational therapists helped with that as well because it was such an important area that I'd started really focusing on in my last couple of years in post. So that's how that turned out.

Q: And then I believe you went on to work with the Independent Living Strategy Group following the end of your post there?

A: No. I went back as a contractor almost straight away, and the main area of work I was involved with as a contractor was working with adult social care on their information portal. The Department of Health had allocated a certain amount of money for local authorities to really improve and beef up their kind of information and signposting facilities for people, and so I did some contracted work for Kingston with that. There was also a couple of areas in the HR part of my job that I was contracted to continue with. But it was a fairly small amount of work over a fairly short period of time, by which I mean something like a year, no more than a year. I was in hospital in November 2009 and I didn't do a huge amount of contracted work for Kingston after that. One of the other projects that I started to undertake after I left was managing the re-doing of KCIL's website. Obviously that was a voluntary job. We did manage to produce something that worked better than the previous one, and I think--, I think it might be running on vaguely the same basis now. But after I came out of hospital in November 2009 I wasn't able to do so much of that either. And then in 2010, I think it was, I decided to enrol on a disability studies course by distance learning from Leeds University, and I think it was in 2011 I got a postgraduate certificate in disability studies. I found the work really interesting, but writing long essays in the splendid isolation of home rather tricky so I didn't carry on and did the MA. I just did the certificate, that was one year. I'd wanted to do something like that for a long time and I found it really interesting. Independent Living Strategy, I'm not sure what you mean.

Q: Oh sorry, it was the--, is it the group that Jane was involved with or no?

A: Yes, I can't remember how long the Independent Living Group has been going, but it was Disability Rights UK that set it up, maybe two, three years ago, I can't remember. I'm still a member of it but for various reasons, including a long and protracted house move, family reasons, etc, I haven't actually been able to get to the meetings up in London. But Jane Campbell refuses to let me resign so I just stick my two pennyworth in my email when the mood takes me, as it were. I would like to get back to that more but at the moment that's the situation. What I did do a lot of after the coalition government came into office in 2010, I did a lot of campaigning, a lot of campaigning mainly on welfare and mainly on 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 for 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. I was interviewed by television channels a couple of times. And the way that I and a few likeminded campaigners worked was not the kind of DEPAC 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 than 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 [laughs].

Q: Very frustrating.

A: 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 20 metres issue with PIP, although that wasn't--, one of the bedroom tax cases was ultimately successful and [inaudible 1:01:30] in court a few weeks ago, but the PIP case wasn't successful. We did force the government to do another consultation though, which they didn't listen to the responses to 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, and writing for the newspaper and being interviewed for the television were definitely things I hadn't done before.

Q: What would you say is your proudest achievement of all the work that you've been involved with?

A: I think my proudest achievement is a lengthy solid report for an organisation called Just Fair on the extent to which the rights set out in the United Nations Convention on the Rights of People With Disabilities have been respected in recent government policy, by which I mean the welfare reforms, the legal aid reforms and the social care reforms in the shape of the Care Act. I think that's my proudest achievement. It was a humungous amount of work. I was working with trustees of Just Fair, who are professors and university lecturers, so I couldn't get away with anything that was very slightly incorrect. So it was a very exacting task, it was a very demanding task, but it was also interesting and fulfilling in terms of doing a consultation online with disabled people and also using other research and reports to build kind of an argument for supporting the thesis that these rights have not been respected in the reforms that have happened since 2010. That itself fed into the relevant committee on rights of disabled people, UN committee, deciding to hold an inquiry in response to a complaint to them about the impact of government policy on disabled people's human rights and also the inquiry itself, because the report I did for Just Fair was one of several key reports that the committee used in addition to discussions with disabled people in the UK to do their inquiry into a very similar area. And that in itself--, that's the first inquiry actually that has been undertaken in relation to any country since the convention was ratified by various countries, and the report out of that inquiry will also feed into the committee's examination of the UK's performance, their regular routine examination they do every few years. Although the UN conventions are not incorporated into UK law, they do have influence, they have some influence in the courts, and so having the opportunity to do a paid piece of work to produce the rigorous report that I did was something I do feel pretty proud of,

although it just took me ages and all of the deadlines I was given I had to extend, but we eventually launched it in July 2014 in Parliament. So yeah, that was one thing. Another thing I did was I gave evidence to a Parliamentary committee on the state of adult social care services for working aged disabled people, because so many in government and media think that social care's really about older people, and social care policy is something that I am very interested in. And Jane Campbell chairs a group, I'm not quite sure what it's called, I can't remember, Independent Living Strategy Group or something, that was started by Disability Rights UK and I'm a member of that, and even though I'm not able to attend I am continuing to be a member of that. So at some point in the future, when life's a little less busy, I'd like to get back into doing work on social care policy.

Q: And what is it that you are doing at the moment?

A: At the moment my paid job, it's good to have a paid job after all this time, is I am a disability qualified member of the first tier social security tribunal, hearing appeals against decisions on people's Disability Living Allowance, Personal Independence Payment and Attendance Allowance, and for that reason I can no longer campaign on that aspect of welfare because it would be a very obvious conflict of interest. I enjoy that job but I don't like the paperwork. We measure the amount of work for one sitting day in centimetres and next week's paperwork is several centimetres high, so I need to get stuck into that. But the job is enjoyable and rewarding. It's hard work because you only get paid for when you're actually there hearing the cases, but you have to spend easily as much time preparing the cases. But at least at the moment it's regular work, because the people are still being reassessed who are currently on Disability Living Allowance, reassessed for Personal Independence Payment, and the rate of appeals is quite high. So there seems to be plenty of work at the moment. I used to sit at the Sutton tribunal when I lived in New Malden and I now sit in the Ashford tribunal now I've moved down to Kent. And the move was fairly seamless. There seems to be plenty of work everywhere. I only do that one day a week though because of all the reading.

Q: Yeah, fair enough. So I suppose my last question is what do you hope to see in terms of sort of future changes for supporting disabled people to live independently, I suppose particularly based on some of the work you see through the tribunals as well?

A: I'd like to see the United Nations Convention brought into British domestic law so that people can take cases in British courts against breaches of the rights set out in that convention. I think that would be a turning point. I want to see support for disabled people, whether that's social security or social care, seen as an investment rather than a drain on the public purse in terms of supporting people firstly to improve and maintain their wellbeing, secondly if they're able to, to be economically productive. And I had an article published today in the Guardian Social Care Network making the argument for that and pointing out that although disabled people-- , working and increasing employment for disabled people was in the Conservative manifesto and provisions relating to social care for older people was in the manifesto, there was no mention of the fact that many disabled people wouldn't be able to go to work were it not for social care support. So I mean, overall I want to see a less dog eat dog society and a society that values everybody, including disabled people, therefore supporting disabled people is an investment rather than a drain. That's what I'd like to see. And within social care services I would like to see a much better understanding of what independent living means. And some of the pioneers in Kingston are very good advocates of the meaning, reality and importance of independent living. It would also be nice to see Kingston come into the fore again in terms of innovative policy and service development in the way that it was back in the '80s and '90s.

Q: Absolutely. Is there anything else you wanted to talk about that I haven't asked you about?

A: Yes. Something else that I'm doing at the moment, which is not something that one can talk about very publically, I'm acting as advocate for two disabled people whose needs are very complex, one in Kingston, who's a mum who has a combination of neurodevelopmental disorders, where trying to get the

social worker to actually understand and believe what her difficulties are was desperately hard but has got easier since she's had more aspects of her condition assessed and diagnosed. And her daughter is disabled, she's on the autistic spectrum, and I want to see social work, social support focus much more on families rather than just individuals. This family that I'm talking about, two people, ever so many professionals involved in their lives because there's all the professionals involved for the child and there's all the professionals for the adult. The other person I'm supporting is a lady who lives in Wandsworth who has very complex needs as a result of multiple sclerosis, including cognitive and communication difficulties. And these are the kind of--, it's the kind of work that doesn't pay anything, doesn't get you any kudos or recognition, can't be discussed publically, but I do always say that I would never take on somebody whose needs were straightforward because they wouldn't need me. It's really, really demanding work, very demanding work, but it is absolutely essential because any kind of advocacy support, if there was any, it's pretty much gone because of all the cuts in funding. So I'm really not sure how people like that are expected to be able to get their needs met if there's nobody to take the hugely long time it takes to understand those needs and help them to communicate them. So I don't talk about that much because it's very personal to each of these ladies, but it's probably one of the most important things that I do.

Q: Thank you very much, Jane. That was so interesting. I will stop the tape there.

A: To conclude, my thought is that--, as you'll have heard, I've done a lot of work around disability and various aspects, 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 an understood at that time and important concept, a borough full of disabled people who have been in the vanguard of persuading local authorities to change completely 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 back in the day who were willing to do something different, spend public money in a different way and change the way disabled people receive support, and therefore free a lot of disabled people to live their lives rather than worrying about their support all the time.

Q: Thank you very much.

[END OF RECORDING – 1:18:44]