

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Campbell
Given name	Jane
Date of birth	1959
Place of birth	Kingston-upon-Thames
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Name of interviewer	Jen Kavanagh
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Q: This is an oral history interview with Jane Campbell, by Jen Kavanagh, as part of Kingston's Centre for Independent Living's Fighting for Our Rights project. The interview took place on 5th May 2017 at Jane's home in Surbiton. Due to a technical fault with the recording, the first minute of the interview was lost. During this time Jane stated that her full name was Baroness Campbell of Surbiton DBE, and her first name is Jane. Her date of birth is [REMOVED] 1959, and she was born in Kingston. Her parents names were Ronald Campbell and Jesse Bull. Ronald was a heating engineer and Jesse was a teacher.

Q: And whereabouts did you go to school?

A: Oh, I went to the dreadful Bedelsford School in Kingston, a school for children with, well, in those days they called it a school for handicapped children.

Q: And what age were you when you first went there?

A: oh, I would say nearly six years old, 'cause it was quite difficult to get me in to any school. No school would take me because they felt disabled children belonged in separate segregated institutions.

Q: And so that's where you started your education?

A: Well, if you could call it an education, yes.

Q: Can you tell me a little bit about what that was like?

A: Well it was a typical special school at that time. The schools at that time were basically places where children would be warehoused for 16 years, where they received a pretty remedial education. There was no curriculum, we didn't follow the national curriculum, so there were no tests, no O' Levels, no A' Levels until my final year when the new, more progressive headmistress, decided as an experiment, to allow two of us to undertake CSE English and art. You can imagine that 16 years of a very basic education was extraordinarily frustrating for a bright young child who was eager to learn and who had the capability to learn like any other child of her age. I look back at that time as the worst time of my life.

Q: What age were you when you left that school?

A: 16.

Q: And what qualifications did you have?

A: I had a CSE in English and art.

Q: And what did you then go on to do?

A: Well I then went to a college that had recently been built, specifically to bring up to speed and teach children, disabled children who had been through the special school system or who had had an accident and become disabled through their young school life. It was pretty much, well, for me it was an indictment on the education system at that time, that they actually had to build a college because none of the special schools were teaching the kids, so it showed how much the education system was not working for disabled children at that time in history. It was a good place to be, for the first time in my life I started learning and I was very, very hungry for knowledge. There were teachers that were proper teachers that could teach academic subjects, and their expectation of us was that we would work hard and achieve A' Levels or O' Levels and either go on to university or an apprenticeship or a trade. The whole ethos of the college was to basically be a crammer for kids who had the possibility to learn and the potential to learn well and to achieve qualifications that they couldn't do anywhere else. 'Cause again at that time further education colleges were not accessible to disabled people, so this was the first purpose built further education college and there I think I can say that my life began to turn into colour, when everything beforehand was black and white.

Q: What is it that you studied there? What qualifications did you get?

A: In a three year period I achieved seven O' Levels and three A' Levels in history, politics, sorry, government and politics, and English. So it shows how eager I was to learn.

Q: And what did you then go on to do when you'd finished those?

A: because I didn't actually get very high grades because it was incredibly difficult to catch up 16 years within three years, the grades were not high enough to go to university and I really wanted to go to university. So I came home and by that time Kingston College for Further Education had put a ramp in the building and there were classrooms that I could actually get into, and although it wasn't ideal and they didn't really meet my needs very well, I was so determined I enrolled and retook the English and government and politics A-levels and I got much higher grades that then allowed me to go on to Hatfield Polytechnic.

Q: And what did you study there?

A: At Hatfield Polytechnic I studied humanities and I majored in history. I then went on to Sussex University where I did a Masters and got a First, so I think it took me five to six years to catch up to what my real potential was, having not had any formal schooling before that. But again, not having any initial learning building blocks, I didn't really have a map of what I could achieve and needed to take every possible learning advantage as it came. So it was a period of a desperate, needs to show the world that I wasn't cabbage, I was a cabbage who had a brain!

Q: Absolutely. Well what decade was it when you were doing your further education?

A: It would be, from when I left school, in '71, and so it was throughout the '70s, I graduated from Sussex University in '82. My Masters was largely based on a dissertation. I wrote the dissertation on the

contribution made by Sylvia Pankhurst to the women's movement because I felt that Emmeline and Christabel had all the historical limelight and publicity and everybody said that it was them and their organisation that were the true leaders of the women's movement, and I questioned that in my study, I've always had a political mind I think. I felt having done some background reading around that area, which fascinated me, I felt that working class women's suffrage efforts did not the kind of attention or recognition for their contribution they deserved. Especially by the feminist historians and movement. Without working women suffragettes it probably would have taken a lot longer to win the right to vote. Because they were the foot soldiers that, you know, made the massive marches happen. So they were the people that largely got arrested, they were the people that made the banners and leafleted, and I think my learning and knowledge about their campaigning activities stayed with me and helped me much later during my apprenticeship in the disability movement. Can we stop a minute?

Q: Yeah, course.

A: During the time at Sussex University, I think was probably my biggest political awakening because as you know Sussex University was a hot bed of student politics. It was the good old days when students actually had some political passion ., I became very involved in the feminist forums at Sussex, so I was probably, primarily focused on being a feminist fighter for women's rights long before I made the same analysis of disabled people, but it was a very good grounding for what was to come, what was to become my later involvement in the disability movement. And I also, realised that, yeah, I could achieve probably much bigger things than anybody would ever dream of setting for me. So having got a First for my dissertation, it was a starred First, I knew I would probably get a job, whereas before destination believed I was destined for some day centre, or sitting at home doing degree after degree through the Open University.

Q: So what is it that you went on to do once you'd graduated?

A: Well, once I'd graduated I probably filled out 100 application forms and they all came back with, oh sorry, we don't employ disabled people, because in those days, you know, (it wasn't that long before the days of no Irish, no blacks, no dogs), it became no disabled people. So it was a pretty tough six months. Eventually I was given a job by a disability charity called Radar, it was the national charity for disabled people, and I was employed, well, I thought I was employed as a researcher or development officer but actually when I got the job it turned out that i was largely a typist doing letters for one of the director's who ran something called Remap, which was a group of engineers who used to go round the country helping disabled people, by making adaptations to assist them get around the house or you know, get in their cars. I realised within a few months that I'd been employed because I was a disabled person, with some high qualifications, but actually they had nowhere to put me, they didn't really know how to employ disabled people because still in those days it was very rare to find disabled people themselves, employed by the charities that were there to represent them but not involve them in any way. And in the end this fed my growing anger that disabled people, you know, did not have their own voice but relied on advocates, so called advocates, to speak on their behalf. That disabled people's issues were largely the--, were largely in the domain of non disabled people/ charities who knew very little about what we truly wanted. So they wanted to help us but they didn't want to help us become individuals speaking on our own. So this confused me greatly. Here I was in a charity for disabled people but I felt as if I wasn't contributing to anything I felt was important for me like rights. Anyway, eventually after seven months they sacked me for being unemployable. they said I was too disabled to be employed and that they couldn't meet my needs. I'm not sure what these needs were because I'd never asked for anything other than a job that would, you know, use my brain and my capabilities and not my physical abilities. What they gave me was something I couldn't do, which was the physical act of typing. And they tried a few things, but frankly the research department didn't want me because they thought that I was too disabled to do the work, but they never articulated what too disabled was. So it was a pretty low point because I had all these degrees and felt that I'd managed to get through university with very little support and now I can get a simple job. University lwasn't like it is now, there were no direct payments to employ a PA, so I had to employ my hall of

residence cleaner to get me up in the morning and put me to bed at night, and use my disability living allowance to pay her. I mean you just--, kids wouldn't think that they could do it now, but it's amazing what you can do when you're so determined to get what you feel you can achieve. And I think it helped that I was pretty bloody minded and very, very super determined. So eventually I did get a job and I got a job, which was the best job I think I've ever had. Wt was working for Ken Livingstone at the then Greater London Council (GLC) as a Disability Equality Administration Officer, and I worked in the Disability Resource Team (DRT) that was set up by Ken Livingston in a very similar way that they set up the women's unit. You will remember that the women's unit, I think there are about 100 officers there that were developing projects to promote women's quality in London, and Ken was wise enough and clever enough to do the same on disability, although the unit was a lot smaller. There were ten of us to begin with, about 25 when we were wound up at the end of the good old days of the GLC. I was a local government officer for five years and went up the tree, oh, significantly from just being an assistant to leading and heading up the disability equality training department. So I, by the time it closed I was running a register of 60 disabled people who I'd taught to become qualified trainers, and wonderfully a lot of people that I trained are now running their own training companies, people like Barbara Lisiki who helped me run the trainers training with , Susan Hemmings, who was very senior in the women's gay and lesbian unit. So yes, it was a very liberating, personally liberating time, and it was my first--, actually it was while I was at Radar, encounter with two people who were beginning to organise disabled people into a disability movement, which was called the British Council of Disabled People, the BCODP.

Q: And who was that, who was it doing that?

A: Frances Hasler who worked at the Spinal Injuries Association, and Mike Oliver. Mike Oliver and Vic Finkelstein between them developed, designed and produced the concept that disabled people are still using, which is called the Social Model of Disability. So basically I met the leaders at a conference and I heard Mike Oliver and Vic Finkelstein speak, and I just remember breaking out in goose bumps all over my body, and literally that light bulb moment of everything falling into place occurred. That we were not the problem, that it was society that was the problem, and the only way that we were going to change the system is by organising on our own, away from the infiltration of the do gooders, and I began to understand my place in society and I was captured by radical thinking and radical speaking, you know. The enemy was the charities, the enemy were the social workers, and if we were going to--, if we were to become liberated from the oppressing state that they put us in, we had to do it on our own and that's where it all began, that was in '81-2, the year the BCODP was born at a conference in Europe through the European network of independent living, and disabled people used to, began to look to other parts of the world and we learnt a lot from the American Disability Movement . During the period of my involvement with the GLC I met probably all the people who are significantly involved in organising the disabled people's movement in Britain, and we had different sections, some wanted to bring down the special school system, some wanted to concentrate on employment and access to employment and getting a job and how we were going to sort of take over the charitable industry. Others wanted to bring down charity and fundraising, so there were the big telethon demonstrations. I was more interested in getting anti discrimination legislation and I began sort of developing ideas for that. So I worked, a lot with Mike Oliver and Stephen Bradshaw (Spinal Injuries Association CEO), and we began to devise ways in which to get some funding to write the, to write a significant alternative to the idea that disabled people were innately at a disadvantage due to their impairment. So we needed to write not only the concept of the social model but also think about ways in which we could embed that into the infrastructure of society. So we would need to talk about and explain to society that it wasn't individual acts of disadvantage or discrimination that prevented us from participating in society, but that it was actually systemic to the way in which our society was organised. So we managed, through very, very hard campaigning and writing off for grants, to employ somebody called Colin Barnes to write the book *Discrimination in Britain*, a case for antidiscrimination legislation and it was this book that basically was the blueprint of the Disability Discrimination Act, I can give you the full title, reference to that name as well. And so I was highly involved in that and became very interested in how we could then legislate for that. So that was when the campaign for the DDA charity began, and that began out of talks with Mike Oliver, Rachel Hurst, Stephen Bradshaw, Colin Barnes, and so we adopted that as the

moment as our main area for activity. So there were marches, there were sit-ins, people started chaining themselves to buses saying, well you build a transport system that we can't use, so that is systemic, that is a systemic exclusion of our participation. So unlike America we were kind of academic about our approach to disability rights. We deeply analysed what it was that oppressed disabled people, and that was very much inspired by Vic Finkelstein who had been very active in the apartheid movement in South Africa. He had an accident when he was imprisoned for-- well probably not an accident, he got beaten up in the cells for his involvement as a white South African, for involvement with the black civil rights movement, and during the troubles he was imprisoned. I think he was beaten up, became spinally injured, escaped and came to England, and that's where he settled, and he met Mike Oliver, they were the two super kind of intellectuals, and he brought this concept of physical apartheid, you know, "you disabled people, you are as oppressed as black people because you are excluded from society on the simple grounds that you are disabled, nothing more, nothing less". And we were positioned as an apartheid movement, (segregated in schools and services) and that made a lot of sense to me having studied politics. So I was more, I was interested in persuading the government and politicians. Others were more interested in direct action – going and getting arrested, although I did get arrested on one occasion, which was very exciting, and it was at the beginning when the police did not know what to do with us. So I'm sitting in the middle of Westminster Bridge with about 100 other disabled people, and the police didn't know whether to pat us on the head or arrest us. IN the end they sort of arrested us, took us down to the local police station, which was totally inaccessible; so then they took us across the road to a Holiday Inn where they then bought us all cups of tea and we all insisted on being booked!, You know, we wanted our rights read in sign language, that we wanted it to be in braille, that we wanted to go to the toilet, and in the end they just told us to sod off. Later on in our later years they began to take the gloves off because they realised actually we knew what we were doing and that we, absolutely had a right to be doing what we did, so they had to use the same kind of tactics that they used with other civil rights disruptions. In the early years when I was there it was far more fun because they just didn't know what to do with us. So that was a good thing, but on the whole I used to go to the meetings in Westminster with MPs to try to persuade them to bring in Private Members Bills, da-di-da-di-da, so that was one of my interests, my main interests. Later on I became quite interested in independent living, and through probably my personal experience of falling in love, wanting to leave home and live with my boyfriend, so if I left home, then who was going to get me up? And you know, I couldn't just pay a cleaner like I did at university and rely on the student fraternity to do the rest, it was now much more difficult. That's when I met Ann Macfarlane, because I rang up the local Kingston Association for the Disabled, or I think that was what it was called, and I talked to her on the phone - I remember saying, "I want a flat, so how am I going to do it?" You know, "Can you not advise me? You are the local disability organisation." And Ann was the one who helped me find my first ground floor flat, and we got to know each other, and my then boyfriend, Once we'd moved in he was kind of caring for my needs, but it was far too much for him and we both worked, and I said to Ann, you know, "How do you get up?" And she said, "Oh, well I have nurses," and I remember saying to her, "Well why do you have nurses? You're not sick, you know, why don't they have assistants who will come and help you?" And so then I started talking to people in the movement about, you know, what other people did, and I found out that a few people had persuaded their local authorities to launder money that they would have spent on home care, through a local disability organisation who would then give the money to the person to employ their own helpers, it was called helpers in those days. So I said, "Well Ann, why don't we start a--, why don't we do that in Kingston?" And she was interested, and that was that, I don't know what date it was, Ann will probably have told you because I was more involved on the national stage, she was very much a local campaigner in those days, she was a local activist. She was known locally, everyone knew Ann, so she was very helpful when it came to my flat, sorting out procedures and processes etc over the months of getting my flat, and we met each other and our conversations would develop. And she was intrigued because I was highly radical to her, she was kind of like, whoa! And I would say, "Well why do you meet, and why are you called for the disabled? You know, we're disabled people, why aren't you an organisation of [emphasis] disabled people? Do you know BCODP?" And she would find me I think quite--, she was quite sort of entertained and rather captivated by me, at the same time as being quite irritated with me, because there she'd been for years doing all this work on her own and very much comes from, 'cause she's older than I am, you know, a long, long history of very oppressive organisations and hospitals, etc., and there was this

youngster coming in and telling her what to do. And I remember saying to her, and I still feel embarrassed to this day, you know, "Why are you still wearing those smocks? You know, you look like you live in a day centre or a care home! You know, why aren't you buying nice ordinary clothes?" And she was so good to me because in a way I was very, very direct to the point of being rude, and yet she put up with me because she had the wisdom to see that I was a breath of fresh air and that together maybe with our different strengths, we could change things in Kingston. So it was a very odd union, 'cause she was still hesitant about upsetting people, whereas it was my, you know, my major state of being. I would go in and start saying and speaking my mind, and I remember I caused such a stir in the early meetings 'cause she'd say, "All right then, if you think these things come to the local organisation, join me." So I said, "Yeah, fine," and I remember those first meetings, they probably thought, who the hell is this? And I'm afraid I probably did that until many years later they said, you know, "You need to go because, you know, you're there and we're doing local stuff, local people need a different approach." But at that time it was just right because I hope I gave Ann what she needed. She wanted to make changes but she was a lone person, who had a job and was connected with the movement on a national stage, I think it helped liberate Ann. So we helped each other in a very unusual way. She probably told you how rude I was when you interviewed her, and right she was too!

Q: [Laughs] So was it at that point that you started putting together your proposal for the scheme?

A: Yes it was, we used to sit round her round table or my round table in our flats 'cause she only lived down the road, and we would plan and plan, we did it all ourselves. We took our proposal to the council, I remember them saying, "Oh no, we can't be doing this!" I don't know how many times they turned us down, but we just kept going back, and it was Jenny Webb's arrival in Kingston as the assistant director with her vision (and our determination) that between the three of us we began to make it happen. Then Roy Taylor came on the scene as director which clinched the deal, not only for Kingston, but later for the country!

Q: What would you sort of describe were the main aims of the independent living scheme when you were putting that proposal together?

A: The aim was to give the control to the disabled person, that they (social services) could assess us in terms of hours of PA need but not make decisions about who we employed and what we did during those hours with our PA. It would be a collaborative process that the assessor would collaborate with the disabled person, to draw up a care plan together. That the people that we would employ would be personal assistants and not carers. That the money would come directly to us so that we would become the employers. That we would account for that money, and develop an accounting system. And that we'd start with quite small sums and we would be assessed, you know, regularly at the beginning to see what we actually needed, and they set it up as a pilot scheme so it wouldn't be for others, just for us to determine whether it was workable and safe I suppose. And so, we agreed to that, but in our minds we'd already established the principle of independent living and believed this would be not a pilot for very long, that it would become a choice, it would be one of the menus of-- on the menu of what was offered disabled people. But we soon realised it also required so much more development, because Ann and I were very capable people, we could keep scrupulous accounts, we wouldn't have a problem doing this, but if we were going to extend this to all disabled people then we had to set up an infrastructure of training, peer support and information. We realised we would have to develop a system of accounting to look at the accounts through an organisation. We wanted that scheme to be within Kingston Association for disabled people and not in the hands of the local authority. So we made a film about it, we had to persuade councillors, we had to basically fight tooth and nail for every extension to take it from a pilot into a mainstream activity, but it helped also that there was a very enlightened director (Roy Taylor), and he and I got on very well and he was very interested in becoming sort of a national president, a national social leader on direct payments, and it was he and I who went on to fighting for the Direct Payments Act, to take it from a money laundering service, (sort of semi legal transaction) to an actual legislative right that would state that disabled people could have the option of a direct payment and that it would be given under various terms

that we developed with politicians. It took 13 years, and it was a Conservative government that brought it in. Hang on a minute [pause in recording].

So if we jump back a little bit, at the same time as campaigning for our own personal assistant support, that Ann and I and the development in Kingston, (it didn't just come about through the thinking of Ann and I), I'd already got a lot of the ideas from BCODP. Because at the same time this was happening in Kingston and in other local authorities throughout the country, other campaigns for civil rights were growing. We'd heard about the illegal laundering of monies to get the people out of a home in Hampshire, the first area to establish direct payments through laundering. It was a man called Paul Hunt who was in that residential home, and this happened long before direct payments came into being in Kingston, it was sort of back in the '70s, and he called for disabled people to come together to basically fight to get out the "workhouse", he called these places, these homes, "the workhouse". And out of that thinking sort of in the '80s, the late '80s, early '90s, we began to devise, you know, the transference of the money that was there to look after us into our own hands, we believe that disabled people should own and should direct their own spending and that it shouldn't automatically go to the so-called professionals to put us where they thought we were best placed, "in our best interests". So it all came out of that basic desire to break free from any charity or any organisation that was controlling us, at the same time as looking after us. And so in the BCODP, which was the only national organisation of disabled people, we believed we owned the representative voice of disabled people. So within the BCODP we had something called the independent living committee that was chaired by a disabled man called John Evans. John Evans was one of the six that broke free from the home in Hampshire and was one of the early first users of a direct payment, a laundered direct payment. So John Evans and myself and Frances Hasler and Etienne d'Abeville who came from the Spinal Injuries Association, and myself began to formulate the legislation for direct payments. So we needed a new body that was going to help develop the policy and the practice that would basically develop a whole new system of delivering social care for thousands of people in this country.

We wanted to keep ownership of the area of independent living, so BCODP established the National Centre for Independent Living. It's a very interesting story, developed again, in my flat back room. A woman called Frances Hasler who was on the Independent committee, and myself, got together one afternoon and we drew up a funding application to the Joseph Rowntree Foundation and a couple of other Trusts, and we asked for the money to set up, to have two or three workers to start a centre that would develop a national policy and practice of independent living. And then we went to the Department of Health, we said, "We want matching funding," and we got it, because this was new, this was a new idea, it had political backing from both the Labour party and the Conservatives because we sold it to them politically in two very different ways. To the Conservatives we said it was all about independence, getting on your bike and doing it yourself, and that disabled people should take care of themselves so that they wouldn't rely on the State. And to the Labour party we sold it as equality of opportunity and human rights. Two totally different narratives, which worked brilliantly, and so they then backed the Department of Health. Whatever government was in, they backed development in this area, and the Department of Health match funded, and I think we got in at the very beginning, enough to get enough to pay Frances and I a job share salary, so I left the GLCA and the training world and I became the co-director of the National Centre of Independent Living, and the Independent Living committee of BCODP were our board. So our board of directors would make sure that we kept the organisation very much a part of the independent living aims and objectives of the moment. So the National Centre of Independent Living, was nationally renowned with very little funding and lots of smoke and mirrors! We made out that we were the authority, and in the end everybody was coming to us so we were being commissioned by local authorities to run training courses, we developed packs on how to become a good PA employer. We ran training courses, conferences, and probably in the early '90s, at the same time as the DDA was being developed and devised, the two campaigns became complimentary and just came together providing many disabled people and power. I'd say that was probably the high point of the disability movement. Money was flowing in, in the end the National Centre of Independent Living was employing 12 people, and we were punching way above our weight because Frances and I were very clever political operators. She was very analytical and I was very good at communications, so I was becoming very well known in the government circles with ministers and

Prime Ministers, so it was a very heady time, probably the most active time of the movement. 'Cause you know civil rights movements go through a cycle. They begin, with the dis-empowered, then argue, and fight, and they get angry, we were separatists, no able-bodied allowed to join ;they then get some of what they set out to achieve, once they've achieved just enough many go on to get top jobs, and the actual movement depletes again. We were no different to the women's movement and the race movement, except in one important way and that was that we were highly, highly organised and structured. We always decided things through democratic elections. We had a sort of trade union culture, because many of the members were from the trade union movement, disabled people involved in that, came in to develop the whole of the democratic structure, and as a result the disability movement is the one that that's remained. Disabled people when they speak are far more structurally connected with grassroots in their campaigns than I would say personally, any other civil rights movement.

Q: What year was it when the centre was established?

A: It was established--, I knew you'd probably say that. Do you know? I'm probably able to send you the actual date. It was around the same time that Ann and I began to develop direct payments in Kingston. It was before--, the centre was when we got the Direct Payments Act, so when was the Direct Payments Act? '94 was it?

Q: Yeah.

A: Six, around that time.

Q: Okay, what resistance did you come up against?

A: Oh God! Well the biggest resistance came from the home care industry because they felt very threatened that we were going to take their jobs away, that we were, you know, they needed us, we were their income and now we were rejecting them and finding our own assistance. Very similar to the old charities, you know, "well they can't look after themselves" attitude. So there was resistance from sort of philanthropic and welfareism, and it was very much part of the overwhelming paternity culture of charitable provision at that time. So it was, yeah difficult to fight as it came from everywhere --, it was the local authority, the home care workers, the people that worked for local authorities to provide care, it came from some charities whose income stream came from running the homes and someone, NCIL was hated by them 'cause we were bringing people out of homes and helping them set up their independent living in the community with personal assistants. So we were a threat to these bodies, we were a threat to the home care industry and we began to be seen as a threat to local authority power. So a lot of social workers found it incredibly challenging, they said that they, you know, "they won't cope", "they will spend the money inappropriately, they might go on holidays and spend money on alcohol instead of care", "we wouldn't be able to cope with all the money, we wouldn't be able to manage our personal assistants" 'cause we, you know, what training had we had? Other unsubstantiated claims like "we wouldn't follow health and safety". It was basically they had no control over us and that was terrifying for them. It was Roy Taylor who helped deal with all that, and so he spoke to a lot of local authority directors of social services, when he became president of the ADSS. He came to talk about the right to take risks on an independent living for disabled people platform and I think with his leadership and his collaboration with us and that trust, we had a very important ingredient for addressing a lot of the opposition. There was always going to be opposition but we were as clever as they were, and the other thing that we did was we managed to get the Joseph Rowntree Association to commission a piece of research that showed it was cheaper for disabled people to employ their own personal assistants and run their own show than it was to provide a home care service. Well you can imagine Home Care UK or Care UK, they were incandescent with rage and fear, and there was nothing they could do about it. And we kept saying, "Look, if you've been good home care workers then you will be recruited by disabled people to become good PAs, what's your problem?" But because, you know they were worried PAs wouldn't join a union therefore who was going to advocate for PAs? It was quite a clash of administrative power, it was a clash of trade unionism versus freedom of

movement and the right to a private life. We were using the Human Rights Act and they were using different trade union and employment law arguments. We thrashed it out around the table and it was ugly at times. I quite enjoyed it personally. I don't think Ann did, she didn't like that kind of what I call very aggressive politics, she found it quite difficult, and it was hard for her because she'd grown up in a system that had frankly abused her for years. So personally she went through, I know she went through a personal sort of--, I don't know what you'd call it but it was the road to hell and back. I loved her for her resilience and getting through all that oppressive 1970s paternalistic baggage.

Q: At the point in the mid '90s, what was the relationship between the organisation that is now KCIL and the National Centre, were you--,

A: Well because I was the co-director and I was also a member of Kingston Association they were very strongly linked, so I think that's why our independent living scheme in Kingston was one of the best, you know, we had high wages for PAs, (course, that all fell by the wayside when, over the years as politics infiltrated and took over, you know, the whole infrastructure of providing care). But we probably still have one of the best because I was so closely associated with NCIL and Ann was so powerful locally. The difficult period we had in Kingston was changing our organisation from a paternalistic, "let's lock the disabled in Kingston, to a centre for independent living". Well why do you want to call it a centre for independent living? We're not, we're an association for disabled people, and you know, most disabled people can't live independently, so we had to fight a lot of the old charitable sort of backdrops that had been part of our own organisation as it was in most of the national ones. You know, when I got there frankly it was as bad as the London, Cheshire and SCOPE, very paternalistic. And I said to Ann, "Why do you allow them to do this?" And she said, "Well, you'd better come and help me then 'cause I ain't going to do it alone, no one person can change it." 'And she was right. Cause it was still largely being run by very well meaning able bodied carers and what's his name, their founder, what was his name? I must have told you the man's name, he was in access, he was into access. But anyway, he was the chair for years.

Q: Do you know how many service users there were at that point in sort of the mid '90s within Kingston?

A: Not many because not only was it hard to get the local authority to do this and to change the culture, but it was hard to get disabled people to believe that they could actually look after themselves, that they could actually take control of their lives and have choice and control. So we did as much work at the National Centre for Independent Living and locally with disabled people, training them, developing them, helping them to believe in themselves as we did with the smashing of the old regime.

Q: Yeah, and how--,

A: So it was very slow, you know, we're talking six, seven, eight, nine as the years went by. I don't know how many people there are now, but in the first few years we're talking about half a dozen people, maybe 20 by the end of it, 50.

Q: Okay, yeah, it's not a huge uptake at all.

A: In other places, more.

Q: Oh really?

A: Because there were very--, Kingston was very traditional, but in Manchester there were hundreds because they were a hotbed of revolution. It depended where you were living and who was, what the council was like. I mean think of Surrey County Council and Kingston, the Royal Borough of Kingston, no, you looked after the poor disabled in our borough. That also drove me mad, it was very class driven, you know, middle/upper class, they love to be in charities helping the poor disabled. It was very hard in one

respect to get off the ground in this borough, and I think if it hadn't have been for the combination of the three or four of us, I'd say Roy Taylor, Jenny Webb, Ann Macfarlane and myself were the key movers and shakers, and that watershed would not have come about without us, without one of us.

Q: Yeah, absolutely.

A: It needed the four.

Q: Well what did you then go on to do from sort of the mid '90s onwards?

A: Well obviously I became chair of BCOOP so I was very, became one of the leaders of the disability movement. So I was doing that throughout the '90s, and then towards the '90s I wanted something bigger, I wanted something more. I began to become very interested in the equality agenda as a whole in the whole women's rights, etc. So I, after fighting for the DDA they set up the Disability Rights Commission, and so I applied as one of the commissioner's and got on to that, so I became very much involved on a national platform, and at the same time I left the National Centre for Independent Living and decided to get a "proper" mainstream job, or what we called in those days a 'proper job out of the movement', out of my kind of comfort zone, and I took my first political appointment and became the chair, the executive chair, the paid chair of the Social Care Institute for Excellence, because I'd come to understand and know social care so well that I wanted to bring the idea of choice and control and self determination and 'nothing about without us' into the social care world more significantly and embed it in social care practice. And so this job came up, it was advertised, it was a big job, and I thought, well I'll just have a go anyway. And I got to the interview and had a very lively interview, and I remember one of the questions was, so do you think you can cope having been involved in the disability movement, how are you going to work alongside ministers and senior social service, you know, social-service inspectors and things like that? How are you going to deal with other issues like childcare? And I said, "Well for me the principles are always pretty much the same, that you have your research development people, you have your practitioners, but society has always forgotten the third pillar, which is the voice of disabled people (the service users)." I said, "Unless you start working together you will never develop a users to take responsibility for their care, you will never put users at the heart of practice." And I also said, you know, believe it or not the cabbage has got a brain. And I couldn't believe that I said that, the words just came out of my mouth! But I remember that so distinctly, two of them just laughed and the other two just looked so shocked that I thought, well I probably haven't got this job, but it was good, the interview was fun. Anyway, they put my name forward to the minister, 'cause it was a political ministerial appointment. It was a big job, it was a £5,000,000 budget, and it was me or the chancellor of Northumbria University, sorry, the vice chancellor, who was up for the job. And so Jacqui Smith, the then minister, Labour minister, said, "Well why should I take the risk of appointing you? Because it would be a very big risk, I could go for the same traditional Chair..." And I said, "Well the reason you want me and the only reason you should appoint me, is if you want to shake up the delivery of social care in this country and if you believe that disabled people have a right to control their own lives or users you need me,". And I said, "And I mean the same for young people, for childcare, they also need more control over their lives," and I said, "And it's the same for people who abuse drug and alcohol, it's the same for children in care. Do you empower the child and family to do the right thing, or do you pour more money into the professionals to perternalise?" Well once I mentioned money she was there and I remember getting the letter saying, we're delighted to offer you the post, and thought, are they mad? They're insane! What have they done? But anyway, I was the founding chair of the organisation and I think we had about two and a million in the beginning, and the turnover was well over seven by the time I left, and for that I was given the DBE. And from there somebody said, "Have you ever thought of going into politics properly and applying to be an independent crossbench member of the House of Lords?" And I thought, well I'm never going to be an MP because that route is just not, it's just too physical for my capabilities, but I'd like to go in the Lords and make a contribution, so I applied and they gave me the job and I've now been there for ten years. it's definitely for me, I've come home, this is where I belong. This is as near to the joy that I had when I was fighting for disability rights, and it's as hard because even though I'm fighting a similar war that I was in the heyday of the disability movement – the only difference is it is the

war inside government politics, not outside. it doesn't get harder than this, it really doesn't, especially now. Most importantly I want to protect what we've achieved and build on it. But when you have a recession at the same time as a very ideologically driven Conservative party, that's the warning lights for disabled people and rights-based provision. And so I'm pretty much back to doing what I did when I left university, which was politics, equality politics, equality human rights, because that's what, yeah, it's what runs through my veins, it's what I'm interested in, it's what inspires me and it keeps me alive! Because I should definitely be dead by now. I've ran some very--, well I think I've made a contribution, in the last ten years I've done my own Private Members' Bill called the Portability Private Members' Bill, where I was able to get the freedom of movement incorporated into social care law, so you can now go from one local authority to another and take your care package with you. So your independent living support infrastructure, your individual infrastructure can now go with you. That was impossible, you'd have to start again when you moved, and it prevented people from moving to be near their friends or family, it prevented people from seeking jobs in other parts of the country. Now we can do that in the knowledge that we are able to keep our support wherever we go, so that was my Private Members Bill, I got incorporated by the government. I also managed to stave off assisted suicide legislation, which I see as one of the evils, the big, big evil threat to disabled people's self worth and emancipation. If I could believe that it would help the one or two people that really wanted to be relieved of their abject suffering and stop there, then I would support it tomorrow, but there's a much bigger, more sinister campaign going on out there that probably people aren't conscious of themselves. But we are very alive to it and they've (Dignity in Dying) tried through the Lords and other means to get permissive legislation through, and I have managed through my position and networking in the Lords, to at least give another side of the story, with the help of disabled people campaigning on the outside. I believe this combination of people has staved off this legislation being passed so far. So I feel I've done something and I continue to fight for independent living and self determination and for people to have enough resources to live, not to just survive.

Q: Absolutely. There probably isn't any such thing as a typical week, but can you sort of talk me through what your role at the moment does involve, or sort of, you know, where you end up?

A: A lot of detailed scrutiny of legislation 'cause the devil hides in the detail. Making alliances and communicating across all parties, you know, I will work and be as critical of the Labour side as I will of the Conservative side, and I will support either side who are doing something that's worthwhile. So a lot of very, very hard networking, coming home and watching copious amounts of box sets to switch off, 'cause I'm so exhausted I can't pick up anything else to read. It's very full on when I'm there and when we have our recess I get my old life back and I can go and see my friends and enjoy my friends. But it's like working at BCODP full time, at a time when we were at the height of our campaign, that's what my life's like at the Lords, and I can't do anything else. I would love to do more things locally but I just had to decide where I can possibly make the biggest difference or do more good, and anyway Ann's so much better at dealing with local issues and local people than I am. I've always been a bit too hot headed and demanding, I think Ann's a much more skilled grassroots negotiator.

Q: She'll be very flattered to hear that I'm sure [laughs]. What would you say is your proudest achievement?

A: Two more minutes, 'cause I've got to go out?

Q: Oh sorry, yes.

A: It's okay. Proudest achievement? So many, I mean--, my proudest achievement is that disabled people still believe in me, that I haven't changed from the moment I was sitting in the middle of Trafalgar Square of Westminster Bridge than I am today in the powerhouse of number ten or talking to a minister, disabled people still trust me and I hope that I have never let them down and I will never cross the line, I will never compromise on our rights. I might negotiate, I might compromise to get to the desired end, but I've got my very, very bright line and so far disabled people are happy to work with me. We do this

together. So my proudest achievement is staying part of the family and being an active member of the family, and not selling out.

Q: That feels like a very poignant moment to end on then, so thank you so, so much for your time.

[END OF RECORDING – 1:13:53]