

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Kashmiri
Given name	Ali
Date of birth	1972
Place of birth	Clapham, London
Date of interview	27 June 2017
Length of interview	01:09:37
Number of tracks	1
Name of interviewer	Jen Kavanagh
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Q: This is an oral history interview with Ali Kashmiri by Jen Kavanagh on Tuesday the 27th of June 2017, the interview is taking place at Ali's home in Chessington as part of Kingston Centre for Independent Living's Fighting for our Rights project. So thank you very much Ali for being interviewed as part of the project. Could we start with your stating your full name please?

A: Yeah, Ali Kashmiri.

Q: And what is your date of birth?

A: [REMOVED] 1972.

Q: And whereabouts were you born?

A: Clapham South.

Q: Okay, not too far away.

A: Okay.

Q: And did you grow up in that area?

A: I lived with my parents until I was four and a half in Clapham and then we moved to Putney until I was just before my ninth birthday, and then I moved--, we moved to Kingston, and I've been in the borough ever since.

Q: And what are your parents' names?

A: Carmen and my dad is Akram Kashmiri.

Q: And what are their professions?

A: My mum was a housewife, and my dad was a bit of a jack of all trades, but he mastered in catering, Indian cuisine, yeah.

Q: Okay, and do you have any siblings?

A: I have two sisters, Sophie and Samir.

Q: And whereabouts did you go to school?

A: I went to Bedelsford in Kingston, a special school. So I was there from 1981 until 1989.

Q: So you started there once you'd moved to the borough?

A: Yeah.

Q: What was your time there like?

A: Mixed really, I think I was at the end of the special school era, so the mentality of lots of protection, it wasn't really about--, the focus wasn't really on education, it was more on welfare, so certainly I wasn't stretched, I felt left out in lots of ways, left behind. I felt that I had more but exactly what more meant at that time I don't know, what exactly what direction I wanted to go in or what I was going to do, and there was certainly a vibe that I probably wouldn't live beyond my school years, so therefore I wasn't a child that they wanted to invest in.

Q: That's okay, 'cause can you explain the nature of your condition?

A: So I have spinal muscular atrophy which is a neurological impairment, that affects the central nervous system, and ultimately muscle development and maintenance, so it's quite--, it's a progressive impairment, but it's slow. And to the naked eye it's unnoticeable, the change, but it's so slow, and obviously it evolves over time, so that's the crux of it.

Q: How old were you when you were first diagnosed?

A: 18 months.

Q: Oh right, okay, and how was it sort of presenting itself, do you know when you were first diagnosed?

A: Well it was my mother actually that had a hunch, and but that hunch wasn't quite good enough for the medical profession, so she had quite a hard time, but then from my diagnosis took place when I was 18 months old, after a long fight, long drawn out battle, and in fact my mum was almost sectioned because of it, 'cause she was insisting that something wasn't quite right, and she was disbelieved and, yeah, and obviously in those days. I mean I say those days, I think it still happens now, in lots of--, perhaps it's a variation on the behaviour and the attitudes, but obviously it boils down to the same kind of challenge that people have, to get the right sort of treatment, or acknowledgement or support even. So yeah, so she had a bit of a tough time, but yeah, that's it.

Q: And once you received that formal diagnosis, I assume that then support was offered, in terms of sort of medical treatment?

A: Yeah, I mean I think, yeah, advances in--, I think it's all relative to the time, I mean obviously the treatment I got would have been better than a child that was born in the '50s say, and a child that's born in

today's era would be--, would receive better treatment than I had. But I think a lot of it is about attitudes, it's about a lot of the challenges we face are because of preconceived sort of ideas and value judgements and is that what--, is that life worth keeping, and having, is that person going to be of any value to society, or are they just going to be a drain on society. So whatever the clinician is, whoever they are, I mean their energy, the vigour that they put into their work, ultimately depends on their attitude.

Q: Yeah, absolutely. And so in terms of your education at Bedelsford, what age were you when you finished there?

A: I was 16 and three quarters.

Q: And what qualifications had you achieved?

A: Well I was quite fortunate in the sense that in the last two years I was at school the school appointed a new deputy head, and who happened to be the English teacher as well, and she was from a mainstream school, mainstream school background, and she was definitely a no nonsense type character, and if you like she raised the bar and she pushed those kids who were capable to a different level. And I think I was one of them, so I came out with some low grade GCSEs.

Q: And did you--, what did you then go onto do, did you go into employment?

A: Well the options that I was given was residential college, or working on a TV production line, television, assembling TVs. Neither of which I wanted to do, and so I rejected every single suggestion that came my way and I spent a year after school just finding out about the world, and that meant, you know, often loitering in Kingston town centre and meeting up with friends and watching films and just generally having a chilled out time. And I went to Pakistan for four months, and then did a bit more finding out about what I wanted to do, and that's when I started to hit problems 'cause I actually wanted to go into electronic engineering, and I didn't quite understand what that meant, but I knew that's what I wanted to do, I wanted to do something technical, where I could use my brain and I could make my own little inventions, perhaps you know, I suppose I--, yeah, I was an ideas person, so I wanted to actually bring some of those ideas alive. But then I started to hit barriers with colleges not wanting to take me on and people started coming out with statements like, well you know, we can't accommodate you here and who's going to help you go to the loo and it was all very basic stuff and or you won't be able to reach the workbenches, we haven't got a low down desk, we haven't got a lift, or you'll be a fire hazard, there were a whole host of barriers that actually stifled my career. I mean maybe I wouldn't have done anything with it, maybe it wouldn't have happened, but the very fact that I hit all those barriers to a young person that's really quite deflating.

Q: What did you then go onto do?

A: Well I got involved in the disability movement, not because I wanted to or because I felt that was all I wanted to do, but I thought, hang on, why have we got all these barriers, what's going on and then I sort of just--, you know, sort of bumped into the likes of Jane Campbell and Ann Macfarlane, Ann was actually a governor at my school so she came to give a little talk, which was really quite fortunate for me because that obviously meant I was going through those difficulty times, and Ann was somebody that I spoke to, and she would give little pep talks, and guidance and point me the right way, and so yeah, it was just like, you know, it was all about accessibility, and barriers, and transport, and no dropped kerbs, and automatic doors, it was all very rudimentary stuff that we take for granted now. So I joined the access committee of what was then KADP, and it was of disabled people, not for disabled people so it had already evolved, I think it was for when I first made contact, and I think it was 1988 or '89, it became an organisation of disabled people. Which was a massive step for the organisation, and a clear message that actually this was about disabled people, and steering the way, and not being passive recipients so yeah. And there it goes, that was the beginning of my involvement. I then went to college, locally in Epsom, and I did a BTEC in something to do

with science and technology, not quite what I wanted to do because it was lots of chemistry but often mathematics, not my strong point, but anyway I scraped a pass. And then I was employed by KADP.

Q: So was it through Ann that you became aware of KADP, had you heard of them before you met her?

A: Yes.

Q: In what capacity?

A: Well I think it was because of Ann, but not through Ann, and I'll explain. I think--, Ann was a governor at my school, and KADP were looking for a young person to join the committee, so through Ann's contact, the director of KADP wrote to the school and the school put my name forward. Probably because I was quite rebellious, yeah, very rebellious [both laugh] and, yeah, and then Liz was the director, she wrote to me, and I didn't actually join the committee, but obviously I became aware of the organisation. I was also involved with the Greater London Association of Disabled People, so we used to use KADP offices to have meetings, so I was beginning to get involved in the politics of it, campaigns, direct action, chaining ourselves to buses and raiding and blocking roads and [laughs] yeah, all of the good stuff.

Q: [Laughs] So by the time you then became a member of staff for KADP, what was your job title, when you were first a full time employee?

A: I was project officer.

Q: Okay, what did that entail?

A: So I was--, I used to service the disability action group, so take minutes, set the meetings up, organise transport for people, and so on. I looked after the equipment loan service, so we used to buy bits of equipment, raise money for it and do fundraising and all sorts, and then buy bits of equipment for individuals, and then loan them out on a permanent basis, so computers, wheelchairs, bath hoists, anything that social services wouldn't provide, couldn't provide, we used to do that. It was quite small scale, I used to answer the phone and make the tea [both laugh].

Q: Very important jobs [laughs].

A: Yeah, all sorts of things really. I think there was a holiday grant scheme, so one of my jobs was to promote that service, and I had to set up an equipment sale board, so a sort of--, an old fashioned version of eBay [both laugh], yeah, and I'm good at eBay, yeah, I love eBay by the way [both laugh]. And what else did I do? Oh yeah, we had a--, we had the KADP car, which was an old Ford Escort Chairman, and that was looked after by KCT, Kingston Community Transport, and so one of my jobs was to promote awareness of the vehicle and make it known to people it was available to be borrowed.

Q: Could you tell me a bit more, I've not heard about that before.

A: Have you not?

Q: No [laughs].

A: Okay, it was donated by somebody, an organisation, and they bought KADP this vehicle, and nobody knew quite what to do with it [both laugh] once we had the keys, obviously there was insurance and who was going to look after it and maintain it, so it was given to KCT to have to use to loan out to groups and individuals, and KADP would allow them to keep some of the proceeds, obviously for maintenance, but whatever was over a percentage came back, and it was coppers really, it was--, in fact I

think it cost more money to keep the vehicle on the road than it got back in revenue, but at least it was a service and it was a good vehicle really for people to just borrow.

Q: How long did KADP have that for?

A: [Sighs] I think it was probably into our--, I'm going to say mid '90s, mid to late '90s because I think when KCT folded it went to liquidation, 'cause it was a limited company and charity and it was a huge controversy really I think. So yeah, the vehicle I think it went to the liquidator, I think [laughs].

Q: Oh well [laughs], nice while it lasted.

A: Yeah.

Q: So who made up the staff at KADP when you first joined?

A: Do you want names or posts?

Q: Either [laughs].

A: Okay, so we had the director who was Liz Orton, we had Mary Hester who was administrator, and there was me, a young 18 year old project officer, fresh out of special school, with no knowledge of anything [laughs].

Q: But lots of enthusiasm I'm sure?

A: Yeah, I was energetic and I was keen and I was hungry to learn. Yeah.

Q: And that was all, it was just the three of you?

A: That was all, yeah.

Q: Oh wow, okay. So how did your role then evolve, what did you then go onto do?

A: Well yeah, I mean we talk about work life balance, I mean I had huge problems at home with the personal care and basic human needs, so work was important for me, 'cause it provided another outlet, it was the foundations of my independence really. But I think it was a bit of a chicken and egg really because there were lots of dimensions to this because firstly I think people knew that--, I think I didn't have very strong academic ability, that was my weakness, I was very good on the phone, I was good with people, I was good in meetings, but you ask me to write a report and I would struggle, you know, which word do I put down first, it was as basic as that, how do I turn a blank piece of paper into something that's going to make sense? Pragmatic, practical, clear thinker, yeah, I could do all of that, great on the phone, great with people, always gave the members what they wanted, and so but I became very deflated because Liz, although she was very good for the organisation, she really was very good, I hated her, at the time. She was a terrible boss, very controlling, if it wasn't her way it was wrong, she used to red pen my work like I was back at school. And although I--, you know, if I was to meet her today I'd say thank you very much for giving me a hard time, because actually she was actually quite good for me, and but yeah I suppose I became quite deflated at the time, if you're going to correct my work to that degree you might as well do it yourself, that was kind of my mentality, right or wrong. Yeah, so yeah, so yeah there was all of that going on at work, coupled with what was going on at home, and so I think I stagnated, that's the truth of it, I think I just got to a point where I was just going through the motions of my day, yeah, and I suppose in hindsight I--, if I had been my manager, I would have got rid of me a long time ago. You know, it was that, yeah, I think the organisation probably could have done better. But yeah, so then I sort of moved out of home, and I got my own place, and I used to burn the candle, top, middle and bottom. Yeah, I'd have KADP as my

day job, I'd go home and do telesales, work through the night, get myself exhausted and then struggle to get out of bed in the morning and that went on for many years, to a point where I actually got quite ill and but obviously it was I had to make ends meet. And that was the crux of it. And it was difficult because I didn't actually ever want to buy my own place, but the system, the fact that in the eyes of the housing department I was adequately housed, meant that I wasn't eligible for social housing, but at the same time I couldn't be at home, so I really had to stretch myself. At 21 I was a property owner, in fact I was under 21, but just. And there we go, the rest is history [both laugh].

Q: In terms of the point in which you moved out of home to live independently, were you then in receipt of support, were you getting direct payments?

A: Yeah, I was, I had--, I'd set everything up prior to it, with the help of Renny, who was a real independent living advocate, yeah. Absolutely believed in what she was doing, she wasn't going through the motions, it wasn't just a job, it was something that I felt that she really believed and she supported and she made happen.

Q: How did that process of working with her and applying for direct payments sort of work from your perspective?

A: Well I mean I knew Renny through work, but we made it a point not to mix the two, when we were working we were working, when it was Ali and social worker/service user, you know, it was a different relationship, and she was very good at that, and respected that and so I wrote to her and in my open letter to her I said, "Renny, I don't want to discuss--, I don't want this to affect working with you and I don't want to discuss my personal life whilst we're working," and she never ever overstepped or compromised, or yeah, which was really super. Yeah, so I feel really privileged that she was around at the time. And then we met up, and then it was my dad that actually put the brakes on, he said no to direct payments, he said no to having PAs at home, so my hands were tied because I didn't really have any support apart from--, yeah, the next stage beyond what I was receiving would be to perish, it was that basic. So I had no choice. But yeah, Renny was great. I remember the day I moved out I just rang her up, yeah, I was the rich kid on the block 'cause I had a mobile phone in those days [laughs] and I rang her and I said, "Renny, I've got to move out today," and it was like she was waiting for that moment. And she said, "Right, I'll call you back, I've got to cancel a few appointments, and I'll be with you," so yeah, we met up, somewhere around 11 o'clock, and we met at KADP, and Liz was great as well, she said, "Well have the week off," and that was nothing to do with my annual leave, she just gave me compassionate leave if you like, and said that I could use the office, it was only a pokey little room but that was the office, she had her own little broom cupboard upstairs. And I could use the phone and do whatever I needed to do, so I did. And yeah, so I arranged an agency, 'cause obviously I didn't have any PAs of my own, and I moved out that day and Renny went shopping with me at eight o'clock at night [laughs] so it was great. Yeah. And yeah, it was just, it was surreal really 'cause there I was going around Sainsbury's in the evening with a social worker, I mean who would do that, who would do that [both laugh]?

Q: And where did you move to?

A: Chessington, just down the road from where I am now, in fact it's just down this road from here, a flat that I had.

Q: And how easy was it to find somewhere accessible?

A: Oh it was dreadful, horrible. In fact I sort of decided in September 1993 that I'd have to move, and I moved to my own flat in January 1994, so it was quite intense, but the flat that I moved into was probably the third or the fourth flat that I saw. And it felt like home, and but there were four steps up to the communal entrance and because it was a repossession, and the bank were a bit nervous about giving it to me, in case I wouldn't be able to make it accessible, and so they declined my offer, and they through the

estate agent said that they weren't going to let me buy it, and they gave it to somebody else. And so I said to the estate agent, "Look, if it happens to come back on the market give me a call," like you do, and yeah, and so I looked at probably another 20 flats after that, it was sort of every day I was looking at one or two places, and then one afternoon there I was sitting in the KADP office and get a phone call from [inaudible 00:33:35] on Surbiton High Street. And yeah, he said, "That flat you saw in Chessington, it's back on the market," so I said, "Not anymore," [both laugh] and that was it, snapped it up. And actually the money that I'd been saving, pretty much all my wage, 'cause I was still living at home and I was actually saving up to buy an adapted--, well to get my vehicle adapted so I could drive, and so I redirected that money and spent it on the deposit for the flat [laughs]. So that kind of--, I was a bit disappointed with that 'cause I really wanted to drive, in fact it was more important to me than a house, but obviously I had to do that, yeah.

Q: And then how easy was it to--, what was the process of them making those adaptations to the property in order to make it accessible?

A: It was all a bit difficult really, in fact the whole journey's been difficult. I mean I used to observe disabled people and think, oh you're just a moaning Minnie, and [laughs] that was my view, you know, I can--, come on, put a smile on your face, come on, it's not that bad. But actually when you start getting into the throws of life and you realise you can't find a house and your PAs giving you a hard time, or they're not turning up or there's recruitment to do, or then you've got to get, you know, something repaired or your wheelchair's broken down and everything is a hard slog, very slowly that smile gets wiped off your face. And I think that that's--, there's a misconception that actually if you have a disability everything gets done for you, I think that's how society tends to think, you know, if they see a disabled person, getting out of a car, they never see the person's rights for that car, they bought it with their own money, oh, you had to pay for that did you, oh I thought, you thought what, you thought I'd get that for free did you, I see. And yeah, you can apply that same mentality to houses and room shares and it's always somebody else behind pulling strings, but actually I think as a disabled person we have to work really hard, really hard, you know, to make an impression at work, you have to go above and beyond often to get noticed, you know, everything is more expensive generally, there are lots of hidden costs attached to disability. And sorry Jen, I've forgotten your question.

Q: I kind of have as well, oh just about having your house adapted and those kinds of...

A: Yeah, so I moved into a block of with nine flats, and it was a private block, and it was a relatively new block, and people--, and it was sort of at the end of the property boom, so it was in the recession, and people had moved there had spent sort of, yeah, touching 100,000 pounds to buy a flat, I picked mine up for 52. So you can imagine, I was new kid on the block, disabled person, and there was certainly a vibe, if not sort of direct speech as well, along the lines of we don't want you here, you lower the tone. But I suppose I was still quite naïve, and that carries me actually, I think if I'd been acutely aware of the prejudices and, you know, the hatred even, I would have probably cowered, but I--, I mean superficially I was very tough and brave and I had a good front anyway. And [interruption].

[Break in recording].

A: Yeah, so before I bought the flat it was run by--, the building was--, it's a leasehold flat, but it would mean that I would be one of the freeholders, that was a freehold building that the residents were effectively the leaseholder and the freeholder. It's quite a nice arrangement really but it also meant that people were--, there was a management company which was the residents, and so I approached them through my solicitor, to say would they have an objection if I were to build a ramp, which they would agree to, or at least superficially. But when it came to making some of the changes they all turned up--, well some of them turned a bit vile. If you like there was--, nowadays we would call it disability hate crime, get bangers on the window in the middle of the night, I had my van vandalised, they would do all sorts of funny things, and it would make me feel as though I shouldn't be there. But that I resisted really and then I applied for a disability--, disabled facilities grant, to get a ramp built to the front door, I had automatic

doors fitted, and some of the internal doors widened, and my bathroom made bigger. But that took probably, I think it was about a year and a half, after I moved in before I could say that it was liveable, manageable. Yeah.

Q: How long did you end up living in that flat for?

A: I was there until 2007.

Q: Oh god, quite a long time then?

A: Yeah.

Q: Yeah, and did you move here at that point?

A: Yes.

Q: I see, so I suppose so going back to when you had first moved into your flat, and you were working at KADP at the time, how long did you then work at KADP for, from then?

A: Oh I was there until 2001.

Q: In what capacity, did your role change?

A: Yeah, I [laughs]--, yeah, I mean the organisation was kind of evolving around me, and I say that because I don't think I was really involved in--, certainly nothing strategic, and I was still that little boy and I was always going to be that little boy because it was my first job, or my first real job. Yeah, I mean prior to KADP I worked at Nerden and Peacock for about three months, as a computer trainee, which was actually just data entry and I got so bored with that. But yeah, so yeah, I think I still had that title of being the little boy even though I was 29 when I left, so I'd been there sort of ten years. Yeah.

Q: Yeah, so what did you then go onto do when you left KADP, what opportunities had come up?

A: Well my job had evolved, for the last sort of four years or three years that I was at KCIL has it had become, and I was information and access officer, or access and information officer, that was it, access and information officer, and so I went for a job as access officer at the London Borough of Harrow, and I managed to blag my way through, and into there and get a job even though I wasn't really qualified to do the job, yeah.

Q: [Laughs] I'm sure you were qualified.

A: Like you do [both laugh].

Q: And how long did you--, well what did that job entail?

A: Well I mean that was great for me really, 'cause I arrived at the organisation, determined that it was a new beginning, at that point it was really like--, and yeah, I think I'd had it with disability movement and politics and the organisation and disabled people, and so yeah, there was a period where I just went my own way. And so I arrived at Harrow on my first day and I was presented with my own office, that sounds very glamorous, but it was just a broom cupboard, and there was a pile of files on the ground, and a filing cabinet, that was it, the drawer was open and there were cobwebs all over the phone, and [laughs] yeah, it was just generally a bit manky [both laugh]. And my manager was typical civil servant, quite stern, yeah, obviously had been around for a few years, and probably just waiting for his pension, and [laughs] he said, "Oh yeah, well I'm next door if you need be," so I had my job description and I had my office, that

spent the day sort of clearing the room and going through some of the files and setting up camp, like the--, and [laughs] yeah, and then I was really pretty much left to my own devices, to make Harrow a more accessible borough. And that was my brief [both laugh], how I delivered on that brief is up to me, but it was superb in the sense that it was 18 hours a week, so I did that in three days, and because I had a blank canvas I was able to define the job, so I spent my time sort of reviewing planning applications, and shaking up the place, that hey I'm here, use me. There was lots of reluctance, it really was pushing water uphill, but in many ways that was the challenge that I needed, it spurred me on, I thought, hang on, you've employed me but you actually don't know why you've employed me, let me show you why you've employed me [laughs]. And so I did lots of policy work, rewriting lots of policy documents, reviewing planning applications, I set up the mayor's access committee, and serviced that, so that meant working with a local organisation of disabled people, and yeah, just generally getting to grips with legislation and national policy, local policy, and then I was around for the introduction of the London plan in 2004. So lifetime home standards, wheelchair home standards, and then sort of I was--, then I--, on my other two days of the week I got into IT, so I became Microsoft certified, and I set up as a voice recognition trainer, so I was doing that two days a week, working full time obviously, three days for Harrow, two days freelance. And yeah, it was great. Then 2005, '04 '05, something like that, I had decided to do my accreditation in access and inclusive design, and so I worked on that for a year, and became accredited, and there we go, that's where I am, now I write for a neighbouring London borough, so I left Harrow in 2009, '08, 2008, and that was a great experience really, working for an organisation that really didn't want an access officer, but they felt they had to have one because it was fashionable at the time. Yeah, and it just gave me so much freedom and independence to grow and to develop and actually to have no guidance at all and to have no manager breathing down your throat. It was just, yeah, I don't think I'd have established that independence, or that independent thinking, so yeah, again it's sort of--, at the time I thought what am I doing here, not appreciated, no one understands the work, no one's interested in the work, it feels like a thankless task. And but yeah I did, and I think that's when--, because there was nobody to critique what I was doing, and I got more comfortable with writing and being able to assimilate information, and write solid reports, and put forward robust arguments, that so yeah it's been a journey, it really has. Yeah.

Q: So in terms of the work that you had then done in Kingston prior to that, so to kind of I suppose set you up in terms of what you felt that you knew what you were doing to an extent by the time you got to Harrow, like had you been involved with sort of access policy writing, because were you involved with some like access guides, surveys and things within the borough and things like that?

A: I was, but again I think there were lots more people involved, like and if you like they were carrying me, although I might have been doing the actual pushing together of a document I wasn't actually writing it, you know, it was taking bits from other places or being advised by people that had been around the block a few more times than me, you know, I was, yeah, I mean I was--, there was lots of handholding going on. So yeah, obviously you draw on that experience 'cause I think sometimes, you know, yeah you reflect on the past, you reflect on that, on people, or on things that people might have said to you and you think, oh you know, what was that, I mean yeah, that was really good, that was eight years ago, but hang on that's really useful today.

Q: Yeah.

A: So yeah. I feel I'm--, I feel privileged in lots of ways, but at the same time it feels like things could have been a lot easier, I feel like it's been a--, been like being on a rollercoaster, you get on and actually there's no place to get off, you just have to stay on the ride, yeah. So yeah, it's been tough.

Q: You mentioned a little bit earlier about being quite heavily involved with some of the campaigns in your early days, can you tell me a little bit more about that?

A: Well I was involved with a group called the Campaign for Accessible Transport, it was back sort of late '80s, early '90s, and that group then evolved into Direct Action Network, which you may have heard

about. But at Campaign for Accessible Transport, I think the name's obvious, it was about making buses, trains and generally getting disabled people noticed, that we are equal members of society that need to get from point A to point B, so yeah, I was involved in meetings and obviously lots of direct action which meant sometimes ending up in the back of a police van, yeah [both laugh].

Q: Were you ever charged?

A: No, no, arrested, and there was a demo in Oxford Street where we'd locked Oxford Street, we brought it to a complete standstill, and the police were called and there was warning after warning that you need to get out of the road and you need to let London flow, if you don't move you will be arrested, if you don't move you will be arrested, and if you don't move you will be arrested. And that went on for about 45 minutes, and then in the end they had to deliver on their threat, and so there were ten of us that were arrested, and went to the police station, I think it was Tottenham Court Road, I think it was about one of the only few accessible stations, and then we were--, we had to attend court and I don't remember what it was but they dropped the charges, and apparently the reason for it was that the court room wasn't accessible [both laugh].

Q: Oh well, lucky escape then maybe?

A: Yeah, yeah.

Q: What would you say was the most successful of the campaigns that you were involved with?

A: I would say that it was that direct action, that actually has resulted in the public transport system that we have today, I don't think there's any other single action that disabled people, or organisations could have or would have done that could have made that more of a--, had such positive benefits, the fact that we could get on every single bus in London, the fact that over ground is largely accessible, underground is certainly on its way to being accessible, we've got black cabs, we've got, you know, roads, pavements, dropped kerbs. That whole movement, that hard graft, that campaigning, that really sacrificing lots of time and energy, I think that's been certainly paved the way and made it happen. So yeah, I feel--, obviously I wasn't--, I was just part of a much bigger network, but yeah, we travelled the country doing all sorts of stunts like that, whether it be for social care or getting people out of nursing homes and care homes, back into the community, you know, the whole drive around direct payments, independent living schemes, I mean I think in Kingston, and again I feel quite privileged that Kingston had direct payments before it was legal, and the fact that when there was, you know, there was a will and Kingston found the way. So yeah, I don't think I can say there was one single action that--, I think it was just sort of the cumulative impact that it's had, and it's quite sad that actually I feel we've lost that momentum, that drive, and I think with everything, unless you keep up that momentum, unless you keep the pressure up things do start to slide. And I think that's where we are at the moment, we're on the decline, or perhaps things are plateauing, I don't know which, but to me it feels like certainly in terms of the support people are getting, or not getting, the fact that we're slipping back into the dark ages and I think now that we haven't got, you know, places like day centres and other kind of community facilities where disabled people historically would have congregated, they're just hiding away at home. And you know, apparently receiving a personalised service, but actually are they getting the service, that's the worrying part.

Q: So I mean from your perspective obviously you still work within the accessibility sector, do you--, what would you say are the priorities in terms of changes you would want to see happen?

A: I think at the moment we have--, we're almost in a state of flux, and we've got the legislation, we've got the policies, some authorities have a dedicated person, others not. And I think it's mainly around sort of housing, and how you--, how one can successfully provide disabled people with a level playing field, so the accommodation, is it affordable, is it really accessible, is there a job available for someone to actually support their independent living. Is there a nearby bus stop, is there--, are the pavements accessible, is

there--, are there--, do they have their own transport, is there a transport network nearby, so it's like a jigsaw puzzle, you have to have the individual components in place in order to say yes, that's going to work for that person. And I mean I do lots of work on housing at the moment and what worries me that beyond sort of my role, beyond planning and beyond building control, what happens to that accessible house, and there isn't a mechanism at the moment to ensure that, you know, a disabled person has access to that information, that you know, a property developer knows where to market that accessible home, so they just get lost, we end up with what I call super houses that end up going to an non-disabled person that says, hey, you know, this bathroom's great, this bedroom's great and they actually don't register that actually they're living in a wheelchair standard house. That's kind of where we are, I think that whole--, there needs to be a shift, there needs to be a robust mechanism where that house could be allocated and that person knows where to look, yeah.

Q: Yeah, in terms of so obviously you work outside of the borough but you still live within the borough.

A: Yeah.

Q: So what is your involvement with Kingston Centre for Independent Living as it is now, are you still involved with KCIL in any capacity?

A: Not as involved as I think I should be [laughs].

Q: In what sense [laughs]?

A: I'd like to be able to do more, I'd like to feel that I could draw on some of my experience, I'd like to feel that I had something useful to offer, but in terms of time and energy realistically I don't have any to give. Which is a shame. I think that in many ways I feel that the organisation could do more and should do more, but I recognise that politically it's difficult. And many ways the organisation is a victim of its own success, and yeah, and the fact that it's changed, it's evolved from being a campaigning organisation into an organisation that delivers a service based on a contact, and that's why I feel there is a compromise. Where you can't upset the people that pay your wage, and that's the crux.

Q: Yeah, fair enough.

A: And I don't say anymore.

Q: Okay [laughs], do you attend like user group meetings and things like that or is...

A: I went to one this week, my first time in like seven, eight years.

Q: Oh okay, fair enough [laughs].

A: Yeah.

Q: So out of everything that you have done over the past few years, what's sort of your proudest achievement I suppose, what do you feel most proud of in what you've done?

A: What, personally or professionally, or anything?

Q: Yeah.

A: That's a difficult one because it's lots of things that I've done, it's lots of things that I'm pleased that I've done, so getting my house, that was a massive achievement, and that was a massive if you like--, that

was an ambition that I fulfilled, I think learning to drive was another big thing for me, and just yeah, it's--, but I mean I said to somebody a few years ago, actually I've done everything in my life that I wanted to do, whether that's true now I don't know. I'd like to do lots of things, mainly around sort of social enterprise, I've got lots of ideas and I feel that perhaps the momentum of drive has gone from the disability movement, and again I think in many ways we are a victim of our own success, that we were fighting for independence, we were fighting not to be a homogenous mass, and that we have the, I suppose melted into society, and we don't come together as a united group anymore in the same way that we used to. So that can be a good thing. And I just think, I don't know Jen, I can't really pinpoint one single thing that I can say was a great achievement. I think that, you know, I've been part of lots of good things, lots of big things, and lots of campaigns, and I think we're all contributors to that success, so I don't want to go on any one thing, I mean obviously on a personal level I've done lots of things. But yeah, I think it's just that it's that group, it's that team, that team spirit that I see, yeah.

Q: Thank you very much. I think that is all of my questions but was there anything else that you wanted to talk about that I've not asked you?

A: I don't think so.

Q: Okay, I shall end it there then, thank you so much.

A: Thank you.

[END OF RECORDING – 01:09:37]