

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Page
Given name	Patricia
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Place of birth	Liverpool
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Name of interviewers	Zoe Perry, Roshani Poudel, Jen Kavanagh
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Q: This is an oral history interview with Patricia Page by Zoe Perry on Wednesday, 17 May 2017. Also present are--,

RP: Roshani Poudel, I'm a second year student nurse.

Q2: And Jen Kavanagh.

Q: The interview is taking place at Pat's home as part of Kingston Centre for Independent Living's Fighting For Our Rights project. So could you please state your full name?

PP: Yeah, it's Patricia Page.

Q: And your date of birth please?

PP: [REMOVED] 1951.

Q: And whereabouts were you born?

PP: I was born in Liverpool.

Q: And your parents' names please?

PP: John and Kathleen Farnsworth.

Q: And what were their professions?

PP: My mother was a housewife and my father was an engineer.

Q: And did you grow up in Liverpool?

PP: I--, we were living in Liverpool till I was eight years old and then we moved down to New Malden in Surrey, and we lived there until I was 16 and then we went to live in Northern Ireland for six years. And then after that we lived in Scotland for three years and then I moved back down to London and got married.

Q: And as part of all of that, where did you go to school, can you tell me about that?

PP: Yeah, I went to school in New Malden, to Burlington Road Primary School and Secondary School. And then when I went to Northern Ireland that's when I started work, started work in IT, that was in 1967 and then I continued working in IT there until we moved to Scotland and I continued in that profession and carried on until 1989 doing that sort of work.

Q: And can you tell me a little bit about your experiences of education?

PP: Erm, well, just--, just State education, GCSEs, erm, didn't want to go to university and in those days it wasn't something that we thought about, not like now, you know, where everybody wants to go to university regardless of what they're planning to do. I couldn't wait to get to work and, erm, yeah, I mean I think it was easier then to find work, you know, there wasn't the pressure on people to have degrees then, it was very much down to your work ethic and your intelligence. And yeah, I thoroughly enjoyed what I did and it paid well. On reflection would I do that again? Mmm, possibly no but, you know, IT work always paid the best and, you know, when you're young you just want money to spend.

Q: And did your work in IT feed into any work that you did later in life?

PP: Erm, I wouldn't say so really, no. When I came out of IT it--, the first job I did that wasn't involved with computers as such was working for the health service in '89 when I started working for a team--, multidisciplinary team for what was known then as community health. And although I did use a computer being part of the team, but no, not really, no, I rather liked the idea of being more involved with people.

Q: And you mentioned that was 1989--,

PP: Yeah.

Q: When you started that work, so how old would you have been at that time?

PP: In '89 I was 38.

Q: And what drew you to working for the NHS?

PP: Or was I 39? No, 38. Sorry, say that again.

Q: What drew you at that time to that form of work?

PP: The job came up and it was--, I knew a physiotherapist at the time who said to me I think there's a job going that would be really of interest to you. My job--, my--, the work I was in at the time, I worked for Ray-Core Electronics in New Malden and they were moving the IT department to Basingstoke and I didn't want to make that move. So when this job came up I thought oh, I don't know whether that would suit me really, but it was something very different and I felt that being a disabled person then it would probably be quite an interesting project. It was only going to be for two years originally, it went on for nine years. And I thought well I'll go for the interview and see how it goes, and then they rang me in the afternoon and told me I'd got the job. And it was part time as well, which was also what I was looking for.

Q: And you mentioned that at that time that you were disabled, did that feed into your decisions much?

PP: Erm, I felt it might, er, I felt it--, I probably could've done the job whether I'd been a disabled person or not, but because it was for younger disabled people from the age of 16 to 64 I felt that perhaps it might help me identify with other disabled people. I'd never worked with disabled people before, I had a car accident in '84 and am paralysed from the chest down and, erm, I'd never met a disabled person before that and so it was all very new to me. And when I went into the job for the disability support team and part of the induction was to go to disability day centres and meet other disabled people with various disabilities, that was quite, er, quite an eye opener for me really. Yeah, it really--, I mean it had been a shock for me myself, but then there were people who had different impairments to myself and opened up a whole new world if you like, yeah.

Q2: How much--, sorry, how much time did you have out of--, in your career when you--, after the accident?

PP: Well I had the accident in January '84 and I was on the spinal unit for six months, 'cause that involved a operation and rehabilitation. So came out of hospital in the June and I did a stage--, it was a sort of back to work on a gradual basis starting in the September, so I was off work from January to the September, yeah. And then went back about--, started off I think it was about two days a week and then gradually went up to five days a week, but part time. Sort of, I think it was about--, I think I worked from about 9.30 till about 3.30, something like that, yeah. I didn't really want to do full time, I found it too much. And then when I joined the disability support team that was about five hours a day, yeah.

Q: And can you tell me a bit more about your work for the disability support team?

PP: Yes, I worked with a--, there was a GP, a speech therapist, occupational therapist, psychologist and myself, and I was the coordinator and information person. So we would get referrals--, we had to promote the team when it first started because people in the community had identified a need for that particular age group to have some sort of support network. There was lots for younger people, for children, and there was a lot for people over the age of 64, but there was nothing in between. So we had--, we worked quite closely with social services, with social workers, we would meet with them periodically, but we would get referrals from either GPs or from hospitals, erm, from social workers actually, I'm trying to think who else, oh yes, various day centres were aware of us, we had put our posters up, we'd done talks on it. There'd been a lot of publicity prior to that, leaflets went out, articles in the newspaper and so people would ring up and say, you know, what sort issues they had and could somebody come out and talk to them. Sometimes it was just really giving them information, very basic, or they would really be part of an ongoing support period of time. It might not be people who were newly disabled, it could be people who'd been disabled for quite a long time but never had the opportunity to, you know, talk through their problems. The GP would sometimes identify issues around medication perhaps that hadn't been looked at before, the psychologist would address issues that hadn't been addressed previously. Sometimes it would just be a simple case of organising their benefits, you know, finding out what benefits they needed or they would come to me for information ranging from wanting to know about holidays, wanting to know about things like house adaptations. A lot of stuff really that social services perhaps should've been doing but for some reason--, one reason or another, it just didn't seem to happen. And then we would discuss people's case once a week and each member of the team would be allocated somebody who was felt to be the most appropriate, I would take referrals over the phone and then we would discuss who the referrals were and who would be the most appropriate person to take that case up. But then we would discuss it and sometimes we'd come up with ideas that needed to--, well perhaps the person who had the referral would come back and want further input from the rest of the team, so it was very much a joint and a real team effort, although there were individual cases, as I say, assigned to each member of the team. And then I just used to keep statistics on what sort of referrals we had, identify areas that needed reviewing, you know, perhaps services that weren't providing--, we would hear through the individuals that perhaps the service

they'd been receiving wasn't really up to standard so we would sort of report back on things like that. Yeah, I mean it all seems like a long time ago now, I should've given that a bit more thought if I'd known you were going to ask me that today. But yes, it was people with all sorts of impairments and as I say, it could be very quick, it could be somebody just saying I want to start driving again but I don't know how to go about it because I'm a wheelchair user and--, or I've got a problem with my arm and we would just simply, you know, give them all the information about the driving assessments, things like that. We always told them about Kingston Association of Disabled People as it was known then, KADP, and we would really just furnish them with lots of information that up until that time they hadn't known anything about.

Q: And you mentioned--, just to back track slightly, statistics, who were you feeding those back to?

PP: Back to the health service, yeah. To be--, to be honest, we did not feel supported, ironically, by the health service, they--, they were funding it but we felt that our manager in particular wasn't really that interested. So we--, we actually operated very much on our own, in fact there were a number of occasions--, there was one occasion when I rang up our manager and said, you know, we haven't seen you for the last couple of months, would you like to know what we're doing and what we've achieved so far? And she came and I was a little bit--, because I hadn't worked in the public sector before I was quite shocked at how lax they were in terms of, I don't know, accountability really. And the rest of the team, of course, had all worked in the public sector and I expressed my views about, you know, we could actually--, I mean there were some days when I felt well, you know, if I didn't show up nobody would even know. And we all felt like that a bit actually, didn't feel that supported. But we enjoyed what we were doing, it was very rewarding in terms of the sort of feedback we got from social services--, who first--, first of all I think they saw us as some sort of rival team, rival organisation, but we tried to stress that we weren't, we were there to work with them and to sort of join up what they were doing, because they were overloaded with things in terms of caseloads. But in essence we actually--, we took a lot of their workload away in the best sense and I think they were quite relieved, after a while they felt quite relaxed about it and we worked closely together. We had some clients in common and other clients didn't need--, feel the need to go to social services so they came to us instead. But yeah, I mean I used to do a report to my manager but whether anything got actually done with them I've got no idea. We just knew that all the clients that we had gave really good feedback, some of them wrote into the health service and said, you know, they were really, really pleased that they had a disability support team and hoped that it would continue, and as it happened it went on for nine years, yeah.

Q: Great. Did any of your clients overlap with other organisations, you mentioned the Kingston Association?

PP: Yeah, some of them--, yeah--, well, we--, a lot of--, all our clients, we told them about Kingston Association of Disabled People. There was also local branches of the MS Society, Kingston Association for the Blind, these are the names--, whether these names are still the same today I don't know, but that's what they were called then. And there was the Brian Gaff, erm, there was a sensory impairment team down at the Crescent Resource Centre which was a day centre for disabled people and we worked closely with them, they had people who were either hearing impaired, sight impaired or both. And there was also SCOPE, there was--, is the day centre still going at Geneva Road do you know, for SCOPE?

Q: I'm not sure.

PP: You don't know?

Q: No.

PP: Yeah, mostly people, you know, with cerebral palsy would attend that day centre, but I don't know whether that's still going. But we used to go there and talk to the--, to the people there, the clients, and when they knew what we were doing some of them referred themselves or their mums or dads might refer

them. And we'd go and see if there was anything we could do, anything we could put in place that perhaps they didn't have. So--, so yes, it was very varied, very varied.

Q: And you mentioned it was like a whole world opened up to you, working--,

PP: Yes, yes, it was--, yes, it was. You know, I didn't know half of--, I mean when I was in hospital, for instance, when I--, going back to when I had my accident and I think within a few days a lady came to my bed and said--, introduced herself as an occupational therapist--, excuse me. And I said oh, what, you mean you--, is that to try and find me a different sort of job? [Laughs]. I didn't know what an occupational therapist was, I thought it was to do with an occupation [laughs]. But she obviously then went into greater detail as to what an occupational therapist did. So I had no insight at all of what went on if you had a physical or mental impairment, you know, I didn't know what was around, what people were doing, what people were fighting for, the difficulties people were encountering on a daily basis until it happened to me.

Q: And do you think your personal experience helped you, you mentioned fighting as well going forward?

PP: Er, yeah--, yes, I would say so. Yes, it did.

Q: Were there any other organisations who--, that you worked with after that?

PP: No, there wasn't. I--, after working for the disability support team, erm, part of--, the other thing that we did on that team was we provided some training--, disability training, myself and the psychologist did some disability awareness training and we actually were invited into Kingston Hospital and we did some training sessions for--, not so much the nursing staff as managers, what were known as CMG Managers at the time. And that went down very well, we did that several times, and then we were told that our team was going to--, they could no longer fund it after the nine years. So, the Chief Executive at Kingston Hospital got to hear about it and asked if I was interested in working for the hospital in what was known then as personnel, now known as HR, as their equality--, or what was called equal opportunities officer at the time. So I ended up doing that and became their equality adviser. And that involved doing equality training, which covered everything from race, disability, all that sort of thing, but I--, my main focus was on the disability side of it regarding employing disabled people, what to do, what not to do, how to interview. Also advising the other HR advisers if any of the staff became disabled, the sort of things they'd have to consider and put into place. Also advise the hospital on things like what they should be putting in their leaflets for patients coming in if they were disabled people. Would also advise--, we then did training for nurses, that was a difficult one because a lot of nurses felt that they didn't particularly need any training regarding disability because they didn't see that as, erm, how can I put it? They didn't quite understand why there should be a focus on it, you know, that all patients should be treated the same, but we--, we had a bit of a battle on our hands to try and get the managers to encourage the nurses to come along. Because nurses that had been there for a long time would say things like oh we've nursed lots of disabled people and we know what we're doing, but we knew that there were areas that were being overlooked and things that were not being considered. And we also--, I mean through Kingston Association of Disabled People and talking to disabled people that I knew, and also having been a patient myself I knew there were areas that were being overlooked. And to be fair, when they did come on the training they gave very good feedback and said that, you know, there were things that perhaps they hadn't considered and it was going to make them rethink for the future, and they'd go away and do an action plan, that sort of thing.

Q: I can see how that would've been difficult, I wonder if you can tell me a bit more about those overlooked areas?

PP: Well, it--, I mean they're so very basic that--, for instance, if somebody was coming along to outpatients and they had a visual impairment, for example, then it's no good handing somebody a sheet of A4 paper with a size ten font print on it saying this is what you do when you go home, this is, you know, this

is your aftercare information. And we tried to point out that in a--, in a situation like that you should know in advance that the patient that's coming for the appointment or coming into hospital has a particular impairment, for example, they can't hear or they can't see. And you need to cater for that person in a way that you're not going to cater for the person who's not got any impairment at all, so for instance, you provide them with some information that's in a larger print or if they prefer it you provide it on--, certainly when I worked there, this is going back a bit now, but you offer the service of having it on a tape so that they would take it home and the information would be there for them. We also tried to encourage pharmacy to provide information in large print as well. Also people who could only lip read that, you know, you would talk to the person, look at them face to face. We tried to ensure that simple things like leaving things close to the bed for somebody that's in a wheelchair, not taking their wheelchair away from the bed but leaving it there if they wanted to get on and off the bed. It was endless really, I could go into so, so many examples but--, but yeah, I mean the training did help and I don't think they do it now, I'm not aware of any training that's going on, in fact I'm-, I've met with Lisa recently because I left--, I left Kingston Hospital about ten years ago, took early retirement, and just after I left they wanted to--, they were being required by government to do a disability equality scheme, each public sector had to do a race equality scheme but also a disability equality scheme. So they approached me and asked me if I would do it as a one off project for them, so I said it would probably take about four months--, four or five months to do. So I agreed to do that and it was a huge amount of work and I asked Ann Macfarlane if she'd like to do it with me, which she did. And that was produced, I think it was about--, I think [inaudible 00:29:24] when I started but it was ready--, it was ready just about six months later, with recommendations. Now, the first thing when they--, when the disability equality group met at the hospital and they looked--, they all received a copy of the report--, of the scheme, a lot of them said that they felt it was too ambitious, that they didn't think they'd be able to achieve very much of it and that in an ideal world--, this is to quote them, it would be very nice to think they could do all that, ranging from access--, physical access to communication issues, erm, various--, various things really that they sort of said oh no, there's no way we can achieve all that. But as I said to them at the time, this is covering absolutely everything and if you set yourself a five year target there's absolutely no reason why you couldn't do what we've recommended. Anyway, so that was that and that was my--, my job was finished there, but I recently saw that Kingston Hospital's--, one of their priorities this year was to address the needs of the Korean community and there was also some other priorities that they had. And it prompted me to think, I'd like to know what they've achieved on the disability equality scheme from all that time ago, eight years ago. And so I contacted Lisa at Kingston Centre for Independent Living and I said I'd be really interested to know, as an organisation I think you're in a good position to be the people to ask the question, I've seen your priorities for this year, we're really interested to know, since you had the disability equality scheme accepted and signed off by your Chief Executive eight years ago whereabouts you are in achieving some of the work that, you know, you were going to undertake. So, Lisa--, this is now quite recent, so Lisa did contact them, the set up at the hospital is a bit different now so all the people I knew then, Director of Nursing, Chief Executive, they've all changed, all new people. So she got a very, erm, a very vague response from the Director--, Deputy Director of Nursing I think her title is, I'm not too sure, saying that who wants to know, why do they want to know and if they do want to know then they've got to apply for a Freedom of Information Act. At this point I saw red and felt that this was totally inappropriate and a rather strange response and rather odd reaction. So Lisa said that she also felt it was a bit strange, didn't quite understand the reluctance, if you like, so she suggested that I went to the office and met with her and we discuss it, so I invited Ann Macfarlane. So the three of us went along and I said I really don't understand what the big deal is, you know, we're simply saying here are all the recommendations that were made with actions plans, it was laid out really, really--, and I'm not just saying it because it was me that, you know, was in charge of the scheme, but I just wanted to know whether disabled people were actually... 'Cause we'd done--, we'd interviewed people, we had focus groups, Ann and I, when I was doing the scheme and some of the feedback we'd had, erm, some people were really upset at their treatment when they were in hospital and felt that they weren't being listened to. People would say no, no, no, you know, we'll move you, we do it this way, and they would say well no, we--, I know how to--, I know the best way to move is--, from the bed to the chair is this particular way, various things like that. So Lisa and I decided that we would put together another email to Duncan whatever his name is, who's the Director of Nursing at the hospital and say look, you know, all we're trying

to find out is, you know, have any of the recommendations been implemented, we'd like to just do a review and it would be very nice to meet with you and have a chat, and we left it at that. And he then said yes he would meet with us on the 6 June, but this week just gone Lisa's contacted me to say that he's now cancelled that and he's going to send his deputy instead but he doesn't know what date it will be, so that's where we are at the moment.

Q2: Sorry, could I--, you may already have talked about this a little bit, can--, who was it that wanted that scheme to be put into place?

PP: Well, it was required--, it was a government led thing for all health authorities, all public sector really, councils, health service, police I guess, all the public sector, yeah, yeah. And the race equality scheme, that was--, that had been done before I left. But that was a much smaller, more easy to manage scheme, with disability it was very--, what you can do, when--, Lisa's got a copy of it and you might like to have a look because within that, just by looking at that, you'll see--, 'cause on one of the sections it's a sort of feedback that we got when we talked to people. When we talked to disabled people, people with sight impairment and hearing impairment, and I put anecdotes in there, the sort of comments that people were giving us when we were talking about their experiences in hospital. So you would probably find that quite useful with this project anyway, erm, certainly from the point of view of when they were receiving a service, you know, in the hospital itself, so yeah.

Q: And when you went round and captured those sorts of anecdotal--,

PP: Oh, awful, really some of the experiences, yeah, yeah. People frightened to go back into hospital, people saying they'd never go back in, they couldn't--, they couldn't cope with the, erm, the lack of empathy or understanding and, yeah, some pretty awful things. I think the main thing is that the hospital from what I know have done a lot of work on learning disability, they focused a lot on that. Now I'm not sure whether that's because there was a high profile case where there was a family I think that were very, very vocal about things that had gone on at the hospital regarding physical--, sorry, PLD. But, what I don't think the hospital understands is that, you know, I don't understand why we're splitting people with learning difficulties and people with physical disabilities into two great, you know, separate sections. Because a lot of the ethos around what they're going to do with PLD there's absolutely no reason why it can't be applied to people with physical disability as well.

Q: And how did you capture that anecdotal evidence, was it survey form?

PP: For what, for...?

Q: Of people's experiences, erm, in hospital--,

PP: In hospital? No, it was face to face. We had focus groups, I did encourage people to write in if they couldn't attend, but we set up focus groups in various places. We went--, we visited the local deaf club, they really had it tough when they went in because the communication side of things was really--, is really difficult for them. We also talked to older people, we talked to people who had visual impairment and people with physical impairment, yeah.

Q: And just to back track slightly, you mentioned Kingston Association for Disabled People a bit, did you do any work with them outside of your role?

PP: I did, yeah. We campaigned when there was charging increases going back, oh dear, I can't remember the date now, would it have been 2002, something like that maybe. You'd need to check with Jen. But yes, we campaigned in the street, we did leaflets, we got petitions, we lobbied the council at meetings--, public meetings. I did a--, I spoke at one of the council meetings--, are you doing an interview with Ali at all--, Ali Kashmiri?

Q: Yeah.

PP: Yeah, oh he'll be very good. Yeah, he'll be a really good one to interview, he'll be ten times better than me, but yeah, he will. But he--, he did a fantastic video diary of--, to show the members of the council exactly what was involved in independent living and what his--, a typical day was like for him from when he got up in the morning to when he went to work, when he got home and when he went to bed. And it was quite a--, I don't like using the word brave 'cause I know a lot of people in the disability world hate it [laughs], but I think--, and a lot of other people--, disabled people felt it was quite a brave thing to do, to open the door if you like on his life--, a day in his life. But he did that with the sole purpose of showing these councillors who just sit there in their ivory towers deciding that, you know, everyone should pay that much more for somebody to help them go to the toilet.

Q: And when you spoke at those council meetings, in what role were you speaking?

PP: As an individual, and my view on, erm, why I don't think people should be paying twice, if you like, to be able to do basic things like have a shower or go to the loo.

Q2: Would you mind--, sorry, I was going to say would you mind just explaining what it was that the council were proposing on implementing?

PP: Yeah, that we--, that we paid a hundred percent of our direct payments, yeah. Yeah, I can't remember the percentage at the time, but they were looking for a hundred percent payment back. As it happened, with--, with our campaign, we managed to--, they decided that it would be 75 percent, so we managed to get them down, so it did make a difference, yeah.

Q: And... were there any other issues that you've had to represent to the council at any other points, or...?

PP: Erm... no, really it was just on--, it was really only about the direct payments, really involved with council as an individual, yeah, or with--, with KADP, or KCIL as it is now, yeah.

Q: And did you have any other involvement over time with KADP outside of that?

PP: Well I was on their committee, erm, their--, oh, I don't know whether it was called the committee or a board, I can't remember now, but I was on that for quite a few years, yeah.

Q: And what was your role there?

PP: Really I was there as a--, the--, as a member of the disability support team and I would sort of get involved with anything that KADP were doing really, anything that--, if they were doing like, erm, days where--, like forums, things like that, I'd get involved with that, helping them do those. Yeah, I mean anything that they were doing, if they needed any assistance with I'd get involved with it, erm, I can't think of anything in particular but certainly campaigning or doing flyers or coming up with ideas, that sort of thing.

Q: Can you tell me a bit more about the forums?

PP: Yes, it was really just getting disabled people together to talk about what was--, what they felt the community was lacking in terms of provision for disabled people, where they wanted to see improvements, just encouraging people to have a voice and actually give them the opportunity to express themselves and then we would feed that back to the various areas that needed to know. Most of it would be back to the council, back to social services usually.

Q: And was helping people with that voice, was that a part of KADP's ethos [at the time 00:46:17]?

PP: Oh yeah, yeah, to give people a voice, to listen to what they had to say and then to act on it and lobby for improvements. Working with the council but also making sure that the council, you know, didn't just say oh yes we'll look into it, but really sort of keeping the pressure on, yeah. And there were some very good people, Jenny Webb that Jen mentioned earlier on, she was a fantastic Director of Adult Social Services. Since Jenny's gone I'm afraid it's, you know, the whole thing is very poor, social workers – non-existent, I don't know, I haven't known for a couple of years who my social worker is, my care manager. I used to have a social worker that really was interested in me, would come round and want to know about how I was, what I'd been doing, was I managing okay, could things be improved. A few months ago I had a student social worker who came round and all she wanted to do was--, wanted to know why I had some money left in my direct payments account and I said well, the reason I've got money left in that account is because if I need--, if I had an emergency and needed, you know, twice the amount of hours for any reason, I've got--, I've managed it so I've got some money there as a sort of emergency pot. No, you can't do that, it's all got to be used up, if you don't use it all up by the end of the month we take it back. She just sat there and went on about finance, I don't think she even asked me once how I was, how was my shoulder since my operation, she wasn't interested in me at all. And when she went I thought well, you know, I'm very lucky that I can articulate, I can speak up, I can represent myself quite well, it just made me feel for the people who can't.

Q: And just to back track again slightly, you mentioned pressure--, putting pressure on in sort of a day to day sense, how did you do that when you were campaigning, for example?

PP: Pressure on...?

Q: When you--, as a board member when you were speaking on behalf of, erm, speaking on behalf of people to--, representing to social services or...

PP: Well really it was--, in those days social services was very proactive and you didn't really have to put a huge amount of pressure on them, they worked very well with Kingston Association of Disabled People and they would listen. But if we did have to put--, when I say put pressure on, it was really a case of--, not so much on social services, it was things like the councillors that were making decisions, I think a lot of councillors before they had their meetings would already have made their decisions if you like, and would be paying lip service to people who wanted to go along and represent or talk or put their cases forward, they'd sit and nod but you knew that they'd already made their decision. But--, but on the odd occasion, you know, sometimes you would win through, it's all about having the right people in the right place doing the right thing.

Q: Thanks for explaining, I think I understand that better now. And so did--, was that--, what forms of communication were you using to speak with councillors?

PP: Well, certainly with--, you can do letters, but there's nothing beats talking face to face, no. But I always--, I'm a great believer in belt and braces, which is talking to somebody but then following it up with a written confirmation, so that when they've left that job--, which invariably happens, there's a written account of, you know, so the next person that comes in, they can't say they didn't know anything about it.

Q: In terms of continuing to support people with disabilities around Kingston, what areas do you think at the moment need work, you mentioned social work support, are there any other areas?

PP: Well I mean truthfully I've not been--, I've not been that active for the last few years for health reasons and a lot of frustration really. The difference between Ann Macfarlane, who you will meet, and--,

[Third party enters].

MS1: Hello ladies.

FS: Hello.

PP: [Laughs]. The difference being that Ann will persevere and persevere--, do you want to close the door? Whereas I started to get really fed up going to things that were organised by social services, they'd have these forum days, you know, where--, workshop days looking at, you know, what did we want from--, what sort of services did we want, how did we want them implemented? And I thought my God, I have been to these so many times and we're all saying the same things over and over again. And the last one I went to was quite a while ago but I said to the director of social services who was there, you know, do you never really get the message, why are we still having these now, you know, have you not been told often enough and is it not just an exercise in saying let's tick the box to say that we had a forum for everyone to talk today. Whereas--, and I said to Ann I'm not coming to any more of these, we tell them what we want, we tell them what they should be doing and then next year we'll be doing the same thing again. Ann will persevere, the difference is I won't, I'll say no, sorry, enough is enough. You can't--, you don't know now what you should be doing you shouldn't really be in the job, but then that's--, I'm quite outspoken and that's the way I am. And there comes--, there does come a point when I say, you know, I'm worn out saying the same thing over and over. Not good--, not good, better to keep going but that's not me.

Q: I guess it's your ability to transfer into action things that you've sort of seen in the past as issues?

PP: Yeah, and I've, you know, I've--, like this thing with the hospital, you know, bringing it back up to date, I just want to stick the needle into them now and say, you know, you've had all this information, you've known what you can do, what have you done about it? And why haven't you done anything about it? But at the end of the day I can't force it--, I can't force it, but I'd like to say to Kingston Centre for Independent Living, you are an organisation with a name, with a focus, I'll help you, you know, as much as I can but, you know, we need to actually move it forward. But as an individual I won't go to any more of these forums because I just don't, you know, it's not for me anymore.

Q: And reflecting back, I guess, about, erm, about stuff that you've done, what would you say is your proudest achievement in all of that?

PP: Well, I don't think there's anything particularly to be proud of. Erm, I think--, I think resolving--, I think resolving a lot of issues for people when I worked on the disability support team, that was good. Looking at the feedback we got, it was all positive, there was never anything negative in all the years that we worked on that team. We made some good connections, we worked well with other providers, we worked well with the clients. At the hospital I think that the training that we did was good, I think the work--, some of the things that I achieved for individuals working at the hospital, employees who had become disabled, and in one particular case somebody who wasn't disabled but needed time off to look after her disabled husband. She came up against a manager who was very inflexible and it took a terrible strain--, put a big strain on this nurse and she was really struggling to cope. And so I intervened and met with the manager and we talked it through and we came to an agreement on reduced hours and over a period of time she had been a very difficult manager, very inflexible, but I'd actually taken it above her and she'd actually--, her manager had got involved, but it all eventually smoothed out and came to a good conclusion. So--, so just things like that, just individual things that you--, the odd thing you remember when you're at work that, you know, you think oh that was good, that worked quite well, yeah. But overall I couldn't say that I'm proud of any particular thing really, just, erm, yeah, I mean it was--, it was quite rewarding but very frustrating, a lot of things are very frustrating and I'm not--, I'm not very good at--, if things don't get done I get quite--, quite impatient really.

Q: And is there anything else that you'd like to mention from...?

PP: Not really, I don't think so. Erm, I think--, I get a little bit fed up with people saying things like oh it's so much better for disabled people these days. They say that all the time and in a lot of respects it is when you look back to 20 years ago, 50 years ago, but people are still having to vocalise it all the time, having to remind people, having to, erm... It doesn't seem to come as second nature to people to consider people with impairments, you're still having to--, not--, well, yes, in some cases yes you do have to fight for it, but it is quite exhausting to constantly remind people and justify why you want something. It's hard to give an example just at the moment, erm, probably not--, you're probably not asking the best person that question, but other people will give you a better answer, other people will give you a good answer to that. I just think that we can't take it for granted that because some things have improved we don't still have to fight our corner, I think that will be something that continues for a long time. And I just--, I'm very lucky that I'm in a position to still argue for things and still get my point of view across. And I was talking to somebody the other day about John Lewis and they were saying to me about Kingston Shopping Centre being so easy if you're in a wheelchair, oh it's so much easier, isn't it, this town's great for wheelchairs. And I couldn't help but say well don't think that happened by accident, don't think that happened because somebody in the council said we must make it this way. I'm sure there are people in the council whose job it is to enable access to be better, but it's only good because people like Kingston Centre for Independent Living got involved. I can remember seeing the plans for John Lewis a long time ago and we highlighted the fact that we didn't think there was enough lift provision. The answer was, well there's loads of--, there's plenty of escalators. And I said well, you know, you can't get a wheelchair on an escalator, you can't get a pram on an escalator, you can get somebody who's walking on an escalator. Anyway, they--, they ignored it and within--, I think it was within one week there were so many queues at the lifts and people couldn't get in the lifts because they were so small, you could only get about seven or eight people in at the very most, but that was no wheelchairs, that was just people standing, no pushchairs. Within a week they'd had to open the service lifts and the service lifts had the big pull sort of metal gates and they had to have somebody employed to open those gates, and that went on while they then had to put in new big passenger lifts. So when people say oh isn't it great that it's all been considered, if you look a bit further, no, people don't always think of it, it's organisations or individuals that will point it out to them. So the fight goes on really, if you want to call it a fight, but yeah, it is I suppose.

Q2: Thank you so much for that, that's so interesting. That seems like a very nice place to finish. Did you guys have any further questions?

RP: No, I think that's everything.

Q: I just wondered, there are a couple of acronyms that might be useful, just when people listen back to the early bits.

Q2: Yeah, of course, yeah, yeah.

Q: A CMG?

PP: Oh, I think that was, erm, what did a CMG stand for? Oh, something management, I can't remember now.

RP: Actually I've got one.

PP: Yeah.

RP: What's PLD actually?

PP: Oh, people with learning difficulties.

RP: Ah, thanks.

PP: Yeah, yeah, sorry.

Q2: Is there anything else?

PP: Yeah, I'm always complaining about people that use acronyms [all laugh]. And I thought I was being clever 'cause I thought well they'll know all that and then I'll impress them by using those acronyms [all laugh].

Q2: [Laughs]. Yeah, it's only anybody else that's going to listen [laughs]. Lovely, thank you very much, do you want to stop this...

[END OF RECORDING – 01:04:14]