

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Sands
Given name	Brenda
Date of birth	1944
Place of birth	Carshalton, London
Date of interview	1 June 2017
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Name of interviewer	Jen Kavanagh
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Q: This is an oral history interview with Brenda Sands by Jen Kavanagh on Thursday 1st June 2017. The interview is taking place at Brenda's daughter's home in Surbiton as part of Kingston Centre for Independent Living's Fighting For Our Rights project. So thank you very much for being interviewed. Could we start with you stating your full name please?

A: Brenda Sands.

Q: And what is your date of birth?

A: [REMOVED] 1944.

Q: And whereabouts were you born?

A: I was born in St Helena Hospital in Carshalton.

Q: And what were your parents' names?

A: My parents' names were George Herbert Lawrence Rossiter and my mother's name was Ellen Alice Rossiter.

Q: And what were their professions?

A: Well, my mother was, well, a housewife really, and my father worked for Sainsbury's in the factory for years, you know, as a supervisor until he retired, long time ago now.

Q: And whereabouts did you go to school?

A: I went to the Willows School in Morden. It's the only school I went to, infants, juniors and seniors.

Q: And what age were you when you finished school?

A: When I started school?

Q: When you finished, sorry.

A: 16.

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

A: I went into banking. That's what everybody seemed to be going into, banking, if they weren't--, there weren't a lot of people actually going on to university in my--, well, not the women. So yes, it was a merchant bank in the City that dealt in gold bullion, for a couple of years, and then I worked for Call Brothers Furnishers doing sales analysis, and then I went on to work for Air Products in New Malden, which is now at Horsham, in credit control, and had my son in between all that. Do you want me to carry on till I...?

Q: Yes, if you can, yeah, sure.

A: Okay. I did a bit of nursing for a while until I hurt my back, and then I got into social work by accident because in 1980 I--, my children were young then and I went and worked as a domestic at Newent House in Browns Road from 5pm till 8pm, and I used to do their teas and do the washing up and clearing away and also did their hot cocoa and whatever before they went to bed. I crammed in a lot in three hours. So that was my introduction to social work. And at the time there was a homecare manager, Maggie Berger, who was watching me with older people and just liked my attitude, I suppose, and she was looking for a fulltime clerical assistant in the home help service, as it was then, in the south of the borough, and she went to her manager, it was a bit easier in those days, and said, "I really like this woman. If she's available can I have her to work with me?" "Yeah, go on, yeah, I like her too" [laughs], just very casually in those days. And that's how I started working for Kingston, like in the--, you know, in the field, as they say, or the social work side of things. And I worked there for a few years as a clerical assistant but at that time they felt that people had to be qualified, so most people had to go off and do what they called the CSS, certificate of social services, which was supposed to be a step below the CQSW, which is the qualified social work certificate. And it was a two year thing, so I was sent off--, Kingston funded me. But in the middle of it they decided that actually the CQSW and the CSS were exactly the same, so they amalgamated it, so by the time I completed it I'd got the diploma in social work. So it was just that time, sort of 1988 to 1990 as it transferred over to one qualification. And it was that time, as I say, I had an eight month placement in a nursing hospital for neurology and was asked to set up a service for people with disabilities under the age of 65, because it was identified that not enough was being done for that client group, if you like. And as homecare service had been developing over the previous couple of years and looking at more--, well, went to homecare rather than home help, so doing more personal care, and that went down quite well, though the people--, and I think KADP, as it was called at the time, were jumping up and down to say, "Look, you know, you're not doing enough for us, people with disabilities," where, you know, if they had homecare services they were being put to bed at 6.15pm or after 10, you know. The district nurse service would not accommodate personal care. They couldn't do it, you know. They had their medical model. So it was just felt that it wasn't enough, the provision of care we were doing, for older people's services and we needed to look more at the needs of people under the age of 65. So that's what my brief was, you know.

Q: Can you tell me a little bit more about the placement that you did when you were doing your studies?

A: Yeah, that was an absolute amazing placement. I had a very good supervisor. She felt very pragmatic. I learnt a lot about, oh, you know, like motor neurone disease, CJD, Huntington's disease, all sorts of really--, Guillain-Barre, really weird and wonderful things that I'd never understood before, so it gave me a basic understanding of the types of disability that people had, and a lot of obviously multiple

sclerosis, a lot of that. But sometimes there was a lot of connection between a physical and a mental problem. So, you know, I did a psychology of a woman that presented as actually physically disabled when she wasn't. That was quite interesting, because she'd been to that hospital on several occasions and some people felt she was putting it on and other people felt, oh, here she comes again. I mean, my attitude was, you know, if you've got to go to that extreme of having a tracheotomy in and having your limbs in a spastic form when there's nothing wrong with you obviously was some cause for alarm whatever you look at it, mental or physical. And that enabled me from that placement to go and visit various boroughs and places of interest, which are all documented in that, that gave me better insight into the needs of people with disabilities. I remember particularly when I was in homecare and people weren't aware of need, I went to see a lady that had muscular dystrophy, very extreme, and she used to have a brush--, you know, she could only tap things out with something in her mouth, very extreme. Because the homecare service at the time, you know, in ignorance, fair enough, and not enough training, had said, "Oh, she's very difficult to deal with." But of course, you know, I went to see this lady and she said, "Well, I don't like my flannel slapped round my face, you know. And despite the homecare saying, "I've been washing faces for 25 years." I like my face washed a certain way." You know, and the indignity of all her personal care being taken off her. So it made her--, she said, you know, "I can't have my hair washed any time that I like." So it made you realise how limited people had and how little knowledge we actually had of actually working with people with disabilities and insight into the real needs and profile of their days. So a huge learning curve, but I was very, very fortunate because that gave me massive insight, at the national hospital, of all sorts of physical disabilities and, you know, disabilities related to, yeah, mental health as well, so that link there. So that was an amazing placement, that was, learnt all sorts of things, like ataxia, dysphasia and all that. And we used to have, you know, meetings with the consultants and the nurses and things, and they would go into like, "Well, this lady's got left sided dysphasia and dyspraxia here." And they'd be--, they used to say, "And for Brenda's benefit, she's got a twitchy nose and a wonky leg" [laughs]. I'm thinking... [laughs].

Q: Must have been quite the learning curve.

A: Yeah, well, I think they sort of got the measure of me in no time really [laughs]. So yeah.

Q: So once you were working within that team, what sort of was happening in terms of that transition between what you were saying was home help and homecare? Could you talk me through that?

A: Well, we had a meeting with KADP, it was all monitored. We had a working party that was set up to look at, you know, what exactly we were setting up, you know, the difference it should be. [Searching through papers] We had a meeting to say, you know, it had to be more flexible because, you know, finishing at 10pm, people didn't want to go to bed between 6pm and 10pm. I mean, it did make you reflect on what exactly we needed. So we looked at developing a service that started at 7am till 11.30pm, with the main carers doing like a shift from either 7am till 3.30pm or 3pm till 11.30pm, alright, so that covered the whole day. In the evening we would have an extra person working from, say, 6.15pm till 10pm, I think we did. So we had people working in the evening that would meet up with the day--, but mostly because of the lifting and handling as well at night time, it could be more difficult. And often they would meet up anyway sometimes, I'd get people working in pairs depending on the level of need really. But we were very conscious of manual handling issues, all this sort of stuff came to light over this period because, you know, traditionally in the past there hadn't been any sort of rules and regulations. That's why we'd got district nurses that had bad backs, you know, because you just lifted and heaved and all sorts of things. So we were very mindful of doing all that sort of thing. Yeah, so we decided that I was going to be given a free hand for two years and I was given a certain number of hours to develop it how I saw fit. So initially we started off with just two men. So my office was in the Crescent Resource Centre at the time, which was a centre for people with disabilities, so that was quite handy because I was available, you know, to be able to speak to people one to one. And initially we weren't sure quite how we would manage and what would be different about our service, but it was found, you know, very useful because of quite a few people with MS who actually were happy to go to bed at 10pm or 11.30pm or something like that. And they got in early in the morning at 7am as well and it went throughout the day, so you could cover things like lunchtime and take

people out to the pub, take them to Chelsea football and even to the theatre, but that was all late at night. But it started really expanding the service then and we looked to see where the need was. And at the time I had staff that--, I could match the staff to the needs of the person. Sometimes you needed somebody to jolly you along a bit, you know, or sometimes you needed somebody who's quite gentle with you, so you could--, you knew the sort of staff that you could send in to help people. Though the major group I think were people with MS, there were a lot of people who were actually looked after. That was the major group, I think, or motor neurone. We actually initiated ourselves into people with cerebral palsy--, because at the time it was called the Spastic Society, and it was interesting because I went to the Spastic Society, their AGM and their committee, and it was all made up of really 70, 80 year old parents who'd been looking after their children, and they stoically didn't want any help. They managed, that was their role. But of course as they got older they physically couldn't help in and out the bath, so we initiated--, it took a while for them to sort of accept the help, but once they did it really took off because we then said, "Well, let us help you with the bathing, something physical, you know, and if you want to carry on with this, that and the other, that's fine." So we managed to assist quite a few people with cerebral palsy, but mostly in the physical and help the--, you know, supporting the carers really. We had a young lad with Huntington's disease and we ended up giving him 13 hours of care throughout the day, and it was very specialised care so we couldn't find any cover because he had to be fed several times during the day because of the movements, it used up a lot of energy and calories, so there's a lot of feeding going on, and specialised knowledge about choking. He died when he was 31. But he did go to the--, at Putney they've got a special unit for Huntington's and they were really amazed that somebody with his disorder, which was so degenerative, he'd still been managed in the community. So it said a lot for the team that they'd managed to actually do all that for a long time. And the interesting thing was also, as it developed--, I mean, it was a very innovative service, I have to say, because when people had been referred from hospital, from the National Hospital for Neurology, they'd say, "What borough do you live in?" Because a lot of people went up there for assessment, to find out exactly what the root of their problem was, then they'd say, "Right, what borough do you live?" I'd say, "Kingston." They'd say, "God, you're really lucky then. You go there, you will get a really good service." But I mean, so a lot of stuff--, I mean, probably if you read--, it'll be clearer if you read all about how we got involved in setting up the hours and the idea and the evaluation I did after a couple of years. But, you know, people that had the service didn't feel it was a service because--, interestingly enough, because the client group was under 65, you had a lot more--, not a lot more but equal numbers of men to women clients, whereas in the home help service it was all women home helps initially, because we were looking at older people and the majority of older people that needed help were women. But as you got to 65 and under, of course, you got an increasing number of men that needed support, so then we had male staff. So that was quite new as well, you know. I had--, did you ever meet Chris Egan at all? He's in Kingston.

Q: No.

A: He's like a--, he runs one of the houses now, you know, the sheltered schemes. I [laughs] interviewed him. He was 19 when he came in, with his cycling shorts on and an earring in his ear, and I thought--, but his sister had cerebral palsy and a lot of his friends were disabled. So he was one of my original--, that's my personal care assistants [laughs]. So then there was--, so we had quite a few men as well as women, and they all worked really well as a team. They had a lot of fun. And it's nice because people had moved on from there, people got moved to social work and management. And like Sam, she's moved on, she later on moved and worked with me in a social work team for older people and things like that. But, you know, when you look back you think, well actually, it was a very good service. But, you know, because I wasn't told not to do anything, just let it flow, the service, and just see where the needs actually gravitated towards, you know, so mostly it was--, I think the great benefit at the time was preventing younger people going into residential care. Because you had the Leonard Cheshire homes, you had quite a lot of young people in their twenties, thirties in a home, because unless you'd got the money to care for you in the community, there just weren't services that were adequate to provide that. So on reflection it was a very good scheme really. I think Kingston are quite proud of themselves for it, aren't they, are the moment?

Q: Absolutely. How did the scheme work from the perspective of a service user? Can you talk me through what their initial contact would be and how they would be assessed?

A: Well, sometimes it was word of mouth, because some of the users used to be at the Crescent Resource Centre and they'd say, "Oh, I've got help, you know, going to bed and that." So initially people identified as probably in need, that were having a bit of homecare service but it wasn't meeting their need and they were being put to bed--, so some clients transferred over from the normal homecare service, over to us so that we could give them more flexible time and things like that. From a service user, I think once they actually accepted support, they were highly delighted from it. Some service users, we had to be a bit devious into putting service in, because--, what I found was, you've got to have a very strong marriage. If suddenly your partner becomes very ill with MS or something that demands a lot of time, a, it's difficult for you to cope and, b, I found the most huge learning curve was the intrusiveness of people coming in morning, noon and night to assist your partner. I mean, if that happened to me I'd be putting the gin bottles away the night before, you know what I mean? I'd have to have a good old tidy up if somebody came in to my partner, I thought, oh, are they going to look at the bottle of wine--, you know what I mean? It's a huge intrusive thing that you don't realise. So unless you've got a very strong marriage, you know, it can be very, very difficult, so you have to really--, really highlighted at the time also carers' needs, and that really came into the assessment. So I had a woman that came to me once, her husband had MS, and she broke down in tears and said, "I can't cope with my husband. He's on the floor. Even the ambulance men were--, he won't let me get the ambulance. He won't have any help. He expects me to do this. I've got two children. I just don't know what to do. I just--, you know, this, that and the other." So I said, "Well, you know, unless he will see me, I can't do anything. You've got to try and convince him--, or anything, because he's blinded to the fact that it's your job to do this and not realising, you know, how ill this is making you." But anyway, what happened was he had some neighbours that--, his wife was going off somewhere and the neighbours used to pop in just to keep an eye, and they couldn't do it either, so she talked her husband into perhaps trying a little bit of our service, just to see. So we went round there, Sam and I went round there and they were just--, obviously, you know--, I mean, we didn't charge for the service, well, because I got permission not to put in a charge for a couple of weeks, just to see how it goes, make or break time. And so I think Sam went in and everything, and whatever she did he was highly delighted with, you see. So I went to see him afterwards and he said, "Oh, perhaps I will have, you know, somebody to help me with lunch, and perhaps I will have..." Very, very, very slow introduction to it. His wife was like over the moon. I think he eventually sussed out what had happened, you know, because we were very discreet on the way we did it. But because I had complete faith that staff would be very good--, because it was like changing the sheets and things like that, so there was a lot of personal care. So that was quite the deepest way of getting a service in. But the service user really enjoyed it once he--, but it's just the initial thing of people accepting help very often is the difficulty, and thinking what can you do, you know. And also it was interesting because the district nurses initially, when I set up the service, were going round thinking, "Well, what does Brenda think she can do?" You know, what sort of--, you know, so they were pleasantly surprised because we were going in to do a lot of assisting district nurses, you know, or going in with them sometimes when there was a medical and physical need and working together, so that worked very well. But initially with any new service, people just are, you know, so critical before giving it a chance, thinking, oh, you know, what do they think they're going to do, we've got this and we've got that, you know. But at the end of the day it was a very successful service. But as it developed obviously it gave people more flexibility but it still wasn't enough, because if people wanted to go to a party and come back at 2am we couldn't do that. There were certain things we just couldn't do, you know. We did our best. So that's at the start of the independent living scheme. The independent living fund initially came out of that government--, I've got the paperwork there, to look at the needs of people in the community, though that's how it slowly drifted across, because Kingston--, there were very--, they always felt they wanted to be first in everything, you know. The second smallest of the London boroughs but they like to think they're first in doing anything, and very often that was good, let's do that. So they initiated the independent living scheme with Kingston. It was called Kingston Association of Disabled People at the time, alongside with those, because--, and we had two women, Ann Macfarlane and--, I forget her name but she initiated the first, you know, financial support. And she, funnily enough, had met--, she was never--, not say supportive of the YPDT. She'd never

had it. It was quite interesting, she'd never had it. But why she did or didn't I don't know. She was an incredibly independent woman, very vocal. So she was one of the first, and there was another lady that actually was set up with this initial scheme, and then they slowly said, "This is what we want to do to give people more and more independence. So we will go in and we'll support them actually buying in their own care." So two things happened. More and more people came off the YPT scheme, taking the hours with them, which converted into money, and also as it developed then they started taking the staff. So, you know, after a period of time, after I left anyway, that's how it moved across. Slowly people who were on the YPDT slowly came off to be given their own money. We still kept people on. There were some people that didn't need a full budget and were very happy just to be helped up in the morning and helped to bed at night and bits in between. So even to this day they've still got the YPDT. I don't know how-- , because funnily enough my other daughter's best friend actually works in it, you know. So it's still called the Younger People with Disabilities Team. It was a specialist team for young people with disabilities but it was a bit of a mouthful so it's just the YPDT and things like that.

Q: And in terms of that team, was it defined that if anybody was under 65 they fell into that scheme, or was there a-- , what was the age bracket?

A: Well, 65 at the time, anybody under 65, that was it. There was a difficulty at one point because people that were attending the Crescent Resource Centre, which was a day centre, were suddenly told, "Well, you're 65, you've got to go off to an older people's day centre." So there was a big hoo-ha, which was fair enough because, well, just because you've hit 65 doesn't mean you're older people, you know. So there was a lot of hoo-ha about, you know, whether they could stay there because of their disability. So I think some people transferred across and they did something else. But yes, but it was between 18 and 65. But also we supported in the practical sense-- , you know, if there was a woman with a disabled child maybe, although we weren't looking at the disabled child, we might help the parent by doing some practical things, if they-- , you know, and this particular woman that I said that we were devious to get in, she had a young family, so we actually went and did about three hours' ironing for her during the week because she felt if the pressure was taken off with the practical tasks she could then help her husband a bit more with the-- , there was always such a mishmash of assessments going on and needs and finding-- , because you would initially go to that person if they were accepting help or not and just saying, "What do you feel is the most important thing for you at this moment?" Because you might think, well, getting up in the morning-- , it's like, "Well no, actually, to get to the library, I would really love to get to the library," you know, something silly like that that would really make my day. "Okay, we'll do that," you know. Not what you think at all. But I was very fortunate because all the staff that worked in the team were really good and they were all really dedicated. They got on well together. And it wasn't like a service in a way because it became quite informal and that helped the user group as well, not feeling like they'd got a service going in, you know. It could be quite casual really, the way the service was done. And they were very good, I was very lucky-- , because, you know, I didn't have a deputy or anything, so I was responsible for the service 365 days a year, morning and night, but because the staff were so dedicated they would-- , I think only once was I worried, about 7am, because one of the staff had had an accident in a car, not serious, and couldn't, you know, start off work, but mostly they would get on with it. They were very knowledgeable staff, you know, about medical issues and other issues, that they didn't need to worry me. They might later on in the day say, "I'm just letting you know so and so," but I very rarely got a call. I did sometimes. Very often I had to go out and help with somebody on holiday or something. I usually got cover, and then it was like all hell let loose, because I was alright with managing but actually doing it... [laughs]. "I'll make the tea there while you get on" [laughs].

Q: It's a very different sort of job.

A: It always seemed to be, "Ooh, Brenda's coming." "Oh god" [laughs]. "Brenda can look after you."

Q: How many people made up the team during those-- ,

A: Yeah, well, we had--, well, I think--, was it about--, I said on there, about 20. We started with two and we ended up with 20, was it... [Searching through papers] Oh, I can't remember now... Yeah, at the height of its success the YPT service employed 20 staff and provided care to 80 users. Today the YPT consists of just two staff and approximately eight users. Mind you it might have changed by now.

Q: And that change happened, like you say, when the independent living scheme launched?

A: Yeah. Oh, you see, this was the original proposal for a specialist homecare service. That might be useful for you to read. So we had service user, Kay Hutchin, and members of the working group. The purpose of the working group, to determine with Kingston Association of Disabled People, service users and non users, the need for a specialist homecare team to assist younger people with disabilities and to consider staffing and managerial issues and to propose the setting up, monitoring and evaluation of a pilot specialist homecare team. I mean, do take this away but post it to me--, because it's worth referring to because I can't always remember now [laughs] when I'm looking, oh yeah, that's right, yeah. So I know it's all there, very concise. It takes you through what the needs were for people with disabilities and disability issues, and how we coped with it and how other boroughs coped with it, you know. So it's service users' surveys and all sorts of things. I got a very good mark for that. It was marketing, you know, so I took a thorough job there. And that was all to do with disability issues. So you can take that away. It's the only copy I've got so I'll get you to post it back to me at some point, but it might be worth referring to.

Q: Yeah, thank you. You mentioned one of the challenges was people accepting the help in the first place. What other challenges would you say you faced when you were working within that team?

A: Hmm, what were the other challenges? I think there was moving and handling. I had to be very, very careful of moving and handling, because sometimes there was an expectation to inappropriately--, because for instance we had a lady with MS and her husband actually physically would move her in and out of bed, but he would ask for help from us. And I said, "Well, we're not going to do that, I'm really sorry. We're going to have to use the hoist." So we got into quite a debate with him because he didn't want a hoist to be used, and I said, "Look, you know, you are damaging your back, but that's, you know, your responsibility. That's up to you to decide, but I cannot afford to risk staff's backs, you know, so I have to go by rules and regulations." So that sometimes was a bit of a stumbling block. What can I say? I can't--, you know, when I reflect back, I can only--, perhaps I'm blind, I don't know. I can only think of positive things, do you know what I mean? I can't think of really difficulties I had, because people in the main were really happy with the service, you know. I can't remember any that really--, you know, they started maybe expecting more maybe and then that leaned towards, you know, independent living maybe, but we--, as I say, we would--, with Guy John, with Huntington's, we--, you know, you couldn't do it now, but we would be going in all day with him--, because his mother, her husband had died of Huntington's. He had a brother also who I believe was clear. But we went--, and it was initially for him, his mother--, who would sit in the chair--, his mother worked up in London, and initially I sent one or two of the young lads in just to sit and watch television with him, you know, and then gradually--, so he didn't feel as--, so it built up, and we got him in a--, he said he'd never go in a wheelchair, and then it was snowing outside. Sam whisked him in a wheelchair and said, "Come on, you're getting in there and going out in the snow," and things like that, and it developed. And we took--, I've got pictures when we took him to Chelsea football. He loved Chelsea. And I've got a picture of him when he was being christened. He wanted to be christened before he died. I've got a picture from that. But I can't--, I'm sure there were some awful things really but I can't--, I mean, I wouldn't say I'd wiped them from my mind, but I think people in the main on the service were really happy with it, you know. And they could swap, because sometimes--, because they knew each other, quite a few with MS--, so like Mike would say to Neil or something, "Do you mind going to bed at 11.30pm tonight because I want to go to bed early?" or something like that, you know [laughs], "Can we swap?" you know [laughs]. "If you're going out can I have your slot?" I mean, it had to finish at 11.30pm, 12am. But people generally knew each other from the Crescent Resource Centre. But I can't think of any that really--, we had some really weird and amazing people with diseases and degenerative diseases and things like that, some amazing--, what was that, you know, that person had got. I remember some guy had quite a disfigurement,

because he was born with his sort of twin--, so he was born with like his twin's teeth out of his face, it was really weird, you know. But generally it was people with MS, motor neurone and people with cerebral palsy that fell into sort of categories as you look back, or muscular dystrophy type illnesses, those sort of categories and the type of help we would provide, you know. It sort of evolved that way, because we just went in with two staff not knowing what can we do, do you want me to read to you. One guy had a coin collection and it delighted him and he really needed it sorting out. He was quite disabled, so we sent along somebody to sit with him and take him to coin shows and things like that, really--, it took on board the social side as well as all the other stuff really. But as I say, the only downside was the knowledge that it could be intrusive to the carers, you know, a lot of this. So I remember one particular couple, he had MS and he stoically wanted to remain at home. His wife wanted him at home. They really did not get on. It was a nice house. She was fed up with the district nurse having to come in because he had to be manually evacuated, and we'd go in and feed and this, that and the other, and there was just a mishmash of people coming in all the time. So I worked then with the carers' officer that just set up in Kingston Care Association, Guy Firth, and I said, "Well, let's sit down with this lady and see how we can...?" So we just started from scratch. We said, "Look, you're aware he's got to have this care." "Yes." "You're aware he's got to have that care, it's got to be done." But in the end--, so what happened in the end, we decided that we wouldn't put any service in for several hours during the day. We'd be able to accommodate it to 1pm and they'd come in, so that she would have a knowledge that that was her time and nobody would come here. So we had to start with very basic need as to what she accepted he needed, building it up to how it fitted in with the way she was and things, because he was very severely disabled, but he refused to go into a home. And I think he died at home actually. But that was the difficulty sometimes, with the carers who were just found it all too much, you know.

Q: Yeah. Did you receive--, was it well supported internally within the council? Did you come up against any resistance from anybody internally at the council?

A: Did I what?

Q: Was there any sort of resistance within the council itself to the work you were doing or budget cuts or anything like that?

A: No, no. As it took off--, well, goodness me, as it took off it was like--, well, because it was different and because the staff I had, you know, were good staff, they had good supervision, they knew that I could support them. There was resistance initially, like, as to the staff I employed, like, because it was such a new deal having men, especially young men, but they were just amazing. They were so good, absolutely so good. There was a bit of like, I suppose, eye opening [laughs], like when it developed, because you'd gone from a home help service, you know, that was employing women and suddenly you'd got these young lads coming in, whisking people off down the high street in their wheelchairs, like, "Hooray for Chelsea," or Tottenham, like that. Taking them off--, on a Friday we used to take them to the local pub, bring quite a few together. And it was before we had mobile phones, I used to have a pager that the clients could have so that they could call, you know, in an emergency sort of thing, an one guy [laughs], he used to page me on a Friday afternoon and say, "Oh, can you get Graham back down here again because my bag needs emptying." I'd say, "Mike, couldn't you have stuck to gin and tonics rather than pints of lager?" [laughs] I said, "You're a bloomin' nuisance" [laughs]. I used to page one of the staff and say, "Guess what?" "Oh yeah, okay, Mike needs emptying?" "Yeah." Right, okay, I'll be on it" [laughs]. So yeah, it was good. I mean, and obviously some people died. But it was a good time because it identified need and it also identified that we couldn't cover everything. It was really broad spectrum what we did do, and we went over and above, because I was allowed to do that, you know, just so that at the end of the time we could look back and say, "That was good," or, "That wasn't good." And then it was a stepping stone to independent living, as I say. Obviously now everybody's got the individual budgets, but that's it really--, but I can't really think of--, you know, hierarchies, as I say, were a bit like--, looking at me like, oh. And we had lots of people writing in actually--, because Jenny Webb was impressed with the fact of a number of people actually writing in to say what a good service it was, which is unusual. You rarely get that. Because they said, "And they needed

more of it," you know, because to be honest it was a pilot project and we needed feedback anyway to see if it was alright, and there was a lot of really good feedback, so we were quite happy with that.

Q: So what year was it that you finished working with that team?

A: Well, I was there--, I think '92 or '93, and the reason I stopped, because they started having a purchaser/provider split, which meant you couldn't--, it was supposed to be the new Conservative way of giving people choice. So for instance, homecare, you had homecare service and that was it. You weren't sent out to agency. So they had what they called a purchaser/provider split, which meant you couldn't assess and provide a service as well. You could go out and assess for a service but somebody else would have to give it, which was against what I'd been doing. I'd assessed the service, I came back and I--, you know, and then I provided the service. I knew who would do what and that. That was probably in a way, I feel, how it was successful, because I had insight into the qualities of the staff and the needs of the clients so I could match that, you know. So they said, "Right, well, your role is going to change. You won't be able to go out and assess people any more. Somebody else will do that and you'll just have to provide the service." And I said--, in hindsight what they should have done was said--, because they had a disability team there, a social work team, so my service--, you know, obviously the disability team were involved an awful lot obviously because of users that had the service. But in hindsight they felt really it should have stayed as it was because I could have actually done the assessments as part of the disability team, you know. It's not that it was a massive service. So anyway that decided me that really it wasn't for me. I couldn't not be with people and just sit and provide a service. So then--, so I think it was in--, I did it for two years or three years--, must have been three years, coming up for three years, and then I got a job as a qualified social worker, working with older people. So I applied for a job there and said I'd like to apply the practice of assessment that I did with people with disabilities to practice--, because it was highlighting also, on reflection now, the homecare people, you know, the homecare service and the staff were getting a little bit fed up [laughs], if you like, with the flexibility of the service I was providing, because it was--, they couldn't have that. They were stoically set in provision of care. So they were a bit like--, not in a bad way, it's just like, "Oh, I wish I could do that with my lady," which they should, they should, you know. So I said, "Well, when I move over I'll try and bring that thought, that philosophy over." And they did try for a while, you know, to look at more what people needed socially as well as physically and mentally. So yeah, so my career ended there and they did get another homecare manager in, but--, nothing to do with me, some people just don't like change, and she wasn't actually--, she didn't stay long anyway. So then the team itself moved on as well to do--, sometimes they moved with the users. When they went to the independent living fund they'd move over or do work with them as well as work for them. And then some people decided they'd like to further their, you know, career in social work and went off to do social work qualifications, things like that. So it was a natural sort of break up really. It came at the right time. And it came at the right time when it was developed and it moved with the sign of the times and moved into people then getting complete flexible care and moving on from my team onto flexible care really. And then, as I say, I worked--, I became a senior practitioner social worker, working with the south team, and, you know, I was deputy manager, and then I was a manager. And then again Kingston--, wanting to be at the forefront, Kingston Primary Care Trust, they decided they would integrate the nursing service with social work service, which was--, so I was managing a team of 50 people, 25 district nurses and social workers and things like that, and it worked very well. It was hard work but it worked very well. But when I retired they disbanded district nurse services, privatised social work again, going round full circle, you know. There's only so many ways you can reinvent the wheel really. So yeah, I mean, it had its place in time, I think, and at the appropriate time really. It was a good learning curve for me, massive experience I got, and I think it helped the staff that I was--, they've all moved on to do bigger and better things, you know. So yeah, it was good, yeah.

Q: What would you say was your proudest achievement from your career?

A: My proudest achievement? Well, funnily enough [laughs] it's nothing to do with--, my finest achievement was when I was a domestic in Newent House, you know, doing 5pm till 8pm. I was trying to do 40 boiled eggs and have them all right, right? "That's too hard, love." "That's too soft." "Oh, that's alright."

It was like Goldilocks and the Three Bears. And to achieve doing 40 boiled eggs at one time and get them all right, that will always stay in my memory. I don't know, I mean, throughout--, I suppose I'm pleased with myself really because I would never have expected to go into social work, and as my career sort of developed, you know, every step I took when I did my social work qualification and then went on to do the postgraduate course on strategic management, I surprised myself as well [laughs]. I'd say, "Ooh, did I do that?" [laughs] So I think it was good that--, you know, my own personal achievement really. But I just loved working with the--, I was fortunate because throughout working for Kingston, they financially supported my development. I didn't have to pay for everything. So obviously they had a lot of faith in my ability to do what I did and, you know, I really enjoyed it. I can't say what my proudest moment--, I've had so many proud moments, but not on my behalf. I've been proud for like staff or people that have worked with me and watched their development really and seen them move on, yeah. So it's good, you know.

Q: What are your thoughts about the current disability support system? Have you kept in touch what is happening?

A: No, not really. I know as far as social work it's all changed, and I know that--, not just those with disability, that individuals now have their own budgets, you know, and I don't know if it's a bigger--, well, I don't know the limit on budgets now. I mean, obviously if you've got a severe disability then presumably your budget's higher than somebody who hasn't. But I know everything's so tight with budgets now, everybody's got their own little budget, and I don't know how they can accommodate it really because you've really got to look at needs rather than wants, haven't you? I mean traditionally I know--, I was speaking to somebody in social services recently, that they've had to go and look at the cards, and they've said some people should never have had the service in the first place, you know. They've had it for years, you know, and they're not properly reassessed, or perhaps the person was quite a dominant person, a bit frightened to take a bit or so [laughs]--, I don't know. But with all the disability issues, I think in general, I think, you know, a massive amount has been done over the last 20, 25 years with disability rights and things. You know, just like public places, everywhere you go now you've got to have a ramp or you can't just have a building that's not disability aware, you know. So things like that I think are really good. But then you've got the other side of it. I always remember, there were a few people with disabilities that didn't want to feel they were disabled, you know. Because years ago they used to think, "Oh, you've got a disability, do you want to go to the Crescent Resource Centre because there's people like you?" And they're like, "I actually want to disassociate myself with people with disabilities. I don't feel like I'm disabled. So it did the thing about people abled, not disabled and things like that. And I know we went to forums where you'd have somebody fighting for their rights to have housing and all this sort of thing, and other people with disabilities said, "Well, there are a lot of people that are able bodied that equally should be having their own..." Do you know what I mean? So sometimes it went completely the other way where people with disabilities didn't feel they wanted to be singled out, you know. "I've got a right to super duper housing because I'm in a wheelchair," and these sort of things. So that used to make a lot of people with disabilities cringe, saying, "Well no, I don't want to associate myself with people like that, you know, fighting for my rights that way, you know." But generally most of the people I think I met--, there were a few that really couldn't handle their disability. There was one guy who had MS, I did a paper on him really. He was diagnosed with MS and he was a solicitor--, because with MS it can be quite a lengthy time with the condition and sometimes you're in remission, and it's less than ten percent of people with MS that end up in a wheelchair apparently. But this guy, he'd quickly within a year gone from shaking to being in a wheelchair and he just could not deal with it whatsoever, so he started very antisocial behaviour. He'd be pooping on the floor when the nurses came because he'd be going for a shit in the corner." And he was really--, everybody said, "Oh, he's a nasty piece of work. He should go in a home. He should do this. He should do that, you know. He's an awful person." But, you know, I thought, well, hang on a minute, he was--, when I spoke to him--, nobody really explained to him what MS was, this was some years ago, and how it would affect him, you know, and things like that. So he was really pissed off with the whole thing. And I said, "Well actually, you're not making life easier by this demonstration really, because you've got people saying you can't cope." I said, "Next thing you know, they'll be whisking you off and sectioning you because you're..." You know, so I said, "Why don't you comply a little bit? The more you comply, the less need you'll

have.” So he did start complying. I got a service in and he was taking him down the pub and all that, so that was alright. He did go into a home eventually because he recognised his need. But he just--, he was so angry with the whole system and the fact that he’d so quickly degenerated within a year of diagnosis to--, you know, that--, so you have to sort of look and see, you know, why the--, don’t just look at him and say, “Oh, he’s a horrible bloke and he’s pooping on the floor.” I think, well, you know, why is he doing that when he doesn’t need to. He’s trying to make a statement here that nobody’s listening to and things.

Q: Yeah. So final question I guess is what do you hope to see happen in the future in terms of care and provision for disabled people? Are there any changes that you feel still need to be made?

A: Well, I don’t think you can do it all at once anyway, and I think as--, well, I suppose I just look on the whole of people in need, not especially disabilities, you know, because I’m talking mental health, you know, people with learning disabilities, physical, they’ve all got their own needs, and all these needs really the government need to meet one way or another. So, you know, whether I’m right or wrong, people with disabilities are equal to people with learning difficulties because they’ve all got needs that are their own specific--, and I’d like to think--, and I don’t know, I’d imagine Kingston still try to strive to support in what way they can, whereas other London boroughs probably haven’t got the finances or haven’t directed their finances in the right direction at all. But I’m sure there are plenty of people fighting for disability rights. It has moved on a long way. I mean, everywhere you go now there’s--, I’m sure there’s still a lot of stations where you still can’t get on a train [laughs] but, you know, they’re having to meet that need, aren’t they, you know, haven’t got a lift or--, so that must be incredibly difficult. But everything you read now to do with services and that, it’s always looking at, you know, disabled facilities, don’t you? Wherever you go there’s now facilities for disabled people. Google whatever, you know, you go to--, you know, I took the kids to Washbrook Farm, you know, where I live, and you’ve got disabled facilities, you know, just going in. Everywhere it’s--, you know, and they will tell you. So, you know, I think a lot’s being done and I’m sure in every area there needs a lot of improving, of course there is, but not just for people with disabilities, you know, across all client groups really. So KCI, what are they trying--, are they trying to look at the history of how--, because this was Kingston Association of--, not it wasn’t, was it?

Q: Yeah, yeah, KAPD, yeah.

A: Yeah, because I said KAPD, haven’t I, because we got together. So yeah, I suppose a few people have died. But it was quite a small group, I suppose, initially, you know. You had a few dominant people that actually ran that. But we didn’t have a lot to do with--, initially in homecare you--, as you develop you were made aware of Kingston Association of Disabled People and they were vocal in saying, “What are you doing in the way of providing support in the community?” And it was like, “Well actually nothing really.” We had a token person with a disability. But yeah, as I say, the Cheshire home was noted to have people of 20, 30 with, you know, motor neurone or whatever, you know, multiple sclerosis. It just wasn’t good enough. But it was the Griffiths Report, wasn’t it, that really made people sit up and say, “Look, you know, enough is enough. We’ve got to look at care for people at home now.” So that’s really--, that’s initiated the whole thing really, us looking at service provision. So, you know, I reflect back that I was in a good--, it was lucky, I was very fortunate throughout my career with Kingston. I was probably in the right place at the right time. I was given a lot of support and I had the right people working for me--, with me, not working for me, working with me, you know. And as I say, that placement, I mean, just was the icing on the cake really. It gave me a lot of knowledge about people and their attitude to disability. Some people--, the minute they say they’ve got MS, they plonk themselves into a wheelchair, you know. Other people go, “Well, I’m not...” Because I remember as a social worker trainee, I had a little office to myself as well, I was on my own and this--, I was only like on this placement, and this young lad came in who was about 22 and I said, “Oh yes, can I help you?” And I knew nothing really about MS. And he said, “Oh yes.” He said, “I’ve just seen my consultant and he’s told me that I’ve got MS.” I went, “Alright.” And he said, “I’ve got to go and see a social worker and she’ll tell me what it is” [laughs]. That was my... “Ooh, er...” And I thought--, because it had implications about telling his girlfriend, getting married, having children, your career, going on holiday, masses of impact, and there I am having been there five minutes, “Oh, go and see a social worker.” “I’m not

a proper one yet [laughs]. I'm just training to be." So you just give them lots of information and--, because he was just like--, he didn't know what it was either. It was just like the medical role, "Right, you've got MS, go and ask somebody what it is" [laughs]. I'll always remember that, ooh dear, you know. But yeah, so I was very fortunate really to--, and I was--, I'll just show you some pictures I have. Oh, this was early days, yes.

Q: These are some photographs.

A: This was when it was a home help service. So we had one--, I forget his name. We had one chap and all the women. This was before it was homecare, it was home help. And Marian Sawyer, she still works for Kingston. Trish Goggin, you don't know Trish, do you?

Q: I don't, no.

A: She's at Kingston Hospital. There's a few other girls. Yvonne Hanerford there, she's a team manager in Kingston now, still a good friend of mine. And that's me as a--, that was playing Father Christmas, and some of the old home helps, when it was a home help service. Sue Todd there, she's retired recently. She was the principal manager throughout my career. These are just home helps. There's more there. There's a lot of these people still there [laughs]. And these were my crème de la crème staff. When I--, yeah, they were. When I had staff working in pairs, in teams of four, people were jumping up and down saying, you know, this isn't viable financially, but in fact it worked out it was. They were what I'd call my crème de la crème team. They were wonderful. And it was very good because you actually helped other staff too. I had a member of staff who was lazy. She'd been sent over from another part of the borough and when she was working on her own she was always ill, and she said that she wanted to be a home--, because they still had a home help service as well. She said she wanted to be a homecare assistant, and like not these but they went, "Oh, we don't want her," because she had a reputation of being lazy, blah, blah, blah. So I used her first as a floater, just to fill in little gaps around, and then I put her with a team, and I think I put her with this team, or one of the team. Well, the transformation was amazing, because she got so much--, because you had staff with you who were innovative, who were keen, who were good, and she--, well, in the end she was one of my best workers. She headed a team of her own. She took so much pride in what she was doing and got so much incentive of working well--, because a year after she joined I said, "Do you realise you haven't been off sick for a year?" She said, "Brenda." She said, "It's the best thing I ever did." She said, "I've never been so happy in all my life." She said, "What a wonderful think, thank you so much." And it happened to two or three people, once you put them in a team of really good workers, the other works aren't going to let somebody shirk, they're going to--, you know. And they enjoyed what they were doing.

Q: Amazing.

A: This was when I retired. They put all these on the wall with my history. There's Sam.

Q: Oh yeah.

A: And Donna doing her impression of Sam. She was brilliant. Right, here's a--, so this is when we took them to church. That's then, yeah. Now that's Chris Egan, he works for Kingston still. That's Sam. Oh, that was Chris, Chris Maclean, he had MS. This is John, he's the one with Huntington's who died when he was 31. That was one of the young carers. And that was Kevin and he was cerebral palsy, and we took them off to Chelsea. This was the team, some of the team anyway, not all of them. And this was John. This was the church, he went to be christened shortly before he died. That's Sam with him. And these were some of the team. Here, this guy, he lives in New Zealand now but he runs an amazing agency of carers and he was actually providing care for Kingston Primary Care Trust in the end, a few years ago. But he was one of my carers, he was funny. But they were quite a young team. I had older people as well, not just young. Yeah, you don't know Yvonne then? You don't know Yvonne?

Q: No, I've not met her.

A: And Marion, they all worked for Kingston. That's Chris Egan, he was dressed up. Sometimes life is a bit of a drag for Chris. This was at John's home. Oh, that was just some of the team now, well, before I retired, the social work team.

Q: Do you know if anybody has the originals of these? Do you know who had the photographs in the first place?

A: I don't know. You can take them if you want. I mean, I don't know if you can shrink them up. They're a bit big, aren't they?

Q: That would be great, thank you, lovely.

A: Well, take that one.

Q: Lovely. I'll just stop the recording there as well. Thank you so much.

[End of recording 1:05:45]