ORAL HISTORY RECORDING TRANSCRIPT
'Fighting for our Rights' project

Surname	Trujillo
Given names	Kay Helen
Date of birth	1942
Place of birth	Southwark, London
Date of interview	30 May 2017
Length of interview	01:04:05
Number of tracks	1
Name of interviewer	Jen Kavanagh
Copyright	© Kay Trujillo

Q: This is an oral history interview with Kay Trujillo by Jen Kavanagh on Tuesday 30th May 2017. The interview is taking place at Kay's home in Surbiton as part of Kingston Centre for Independent Living's Fighting for Our Rights project. Thank you very much for being interviewed today, Kay. Could we start with you stating your full name, please?

A: Kay Helen Trujillo.

Q: And what is your date of birth?

A: [REMOVED] 1942.

Q: And whereabouts were you born?

A: Elephant & Castle in London.

Q: Ah okay. And what were your parents' names?

A: My mother was called Doris Kathleen and my father, Walter Edwin--, Crane, sorry.

Q: Okay. And what were their professions?

A: My mother, before she had me, was training to be a nurse, but that obviously was during the wartime, so when she became pregnant she had to give it up. My father worked on British Rail.

Q: And do you have any siblings?

A: Yes, I've got two sisters, Brenda Pauline married a Filipino, but they live in Spain. They've got two daughters, Michelle and Nicole. And my youngest sister is Gillian Barbara Johnson and she's got

two siblings, which is Andy and… Jenny. I had to remember for a minute--, Kenny, yes, and they live in Eastbourne.

Q: Okay. Whereabouts did you go to school?

A: Obviously in London, but at first I went to a school for the disabled, but I didn't get on very well there because my education was done with my mother when I was very young and I was above their standards, so I was held back, which my mother thought so, so she wanted to me to go a school for the able bodied, which she fought for, which I did for a while, till I was 13 or 14, 15, something like that. And I stayed on longer because they weren't sure what they were going to do with me [laughs], I must admit.

Q: What were the names of the schools?

A: The last school I went to was Venetian Secondary, and it was across the road from King's College Hospital in Camberwell.

Q: So what age were you when you finished your education?

A: 18 I think. I stayed on at school till about--, from there on I went to a college for disabled women, and it was to do artwork, printing, stencil printing. There for three and a half years, but unfortunately I cut myself and it went septic and my arm, the only arm I can use, swelled up very badly, and I thought I was going to lose my arm. But my parents brought my home and I went to King's College Hospital and they saved it there. I had an operation where they saved my arm. That's my education part really, I'm afraid. But the Venetian Secondary, I did take--, not GSEs--, not the--, the one under--, I can't think the name it's called now. It wasn't the highest ones, it was the one below that. I took history and English, which I passed with flying colours, but my arithmetic, I'm afraid, was very bad.

Q: So what did you do once you had finished at college?

A: I came home and took jobs here and there. I worked in a kiosk selling sweets, cigarettes and stuff like that. Then I worked in a cinema, selling tickets, and then unfortunately--, well, I say unfortunately--, I met my first husband, Michael, who had muscular dystrophy, and I became pregnant, and we got married. And I loved the baby, but we were married ten years before Michael died. Then I was free again and I was going to look for work, but met somebody else after about a year and we got married, but unfortunately that didn't last. Am I going alright?

Q: Yeah, yeah.

A: That didn't last. That was five years, that didn't last, because he was violent, and whatever happened I didn't want violence in my house. And then I moved back home to Mum and Dad, who were brilliant. I've got to say, they were fantastic parents. I stayed there--, we were looking for somewhere--, I wanted to live back on my own again, because my parents were getting older by then and they wanted--, their lives were not my life. I wanted to still go out and enjoy myself, so I thought I've got to find somewhere else to live. So I went round to the library where my mum and dad lived and looked for housing associations, etc, then came across Calder Court. So I applied to them, if I could have a one bedroom flat. Took a little while but eventually got back to me and said, "Would you like to come and view this flat?" It wasn't this one I'm in now. It was on the top floor of the block, but it had been empty two years so it was in rather a dilapidated state and I weren't going to take it, but

my father persuaded me to do so because he could help me decorate it and sort it out to be habitable, which we did, and I stayed there for, well, must be half the time I've been here.

Q: Oh wow, I hadn't realised that you'd lived here so long. That's amazing. Where--, sorry, what was I going to ask you? Erm, I've completely forgotten the question now. Could you tell me a little bit about your condition and your disability?

A: Well, you know, when I was born it was wartime, of course, and my mother was pregnant, and the father got--, now he's not my real father. My father was a French Canadian, but my mother let him know that--, this is the story that my mother told me, so if it's true I don't really know, but she said he was flying home to be with her but his plane was bombed and he was killed. But Mum got this telegram--, because we lived in the New Kent Road in London then, and I was--, as I said, my mum was pregnant. But she got the telegram telling her about my father and she didn't hear the doodlebug bomb come down, and it hit that room, threw my mother across the floor and her tummy hit the wall and I fell out, and the house came down. So it was the--, what do you call those men that used to come round with the--, to clear the rubbish--, no, to get people out the--,

Q: Oh, the like wardens?

A: Yeah, they came and took my mother and myself out and brought us to hospital. Of course the lack of oxygen at that time, I've got cerebral palsy, so the part of my brain that's damaged, what makes my limbs work properly. Part of the brain, my education side, like my ears, nose and throat--, as you can see, I can talk, but it seems that it just affected my limbs. And my mum said that she'd took me up to the hospital when I got a little bit older, because she said I wasn't taking notice of what was going on round me. You know like you do with a baby, you have a rattle and you--, I wasn't doing that, so she obviously thought there was something wrong. She took me up the hospital and they just said I was a lazy baby. They kept saying this for about six to eight months. Mum wouldn't believe it, "No, there's something else wrong." "You're worrying, Mother, too much. She's going to be alright. You're just fussing too much." So my mum started giving me exercises. And then another one of her friends said, "Go up to the children's hospital in London." I can't think of the name of it now, sorry.

Q: Great Ormond Street.

A: That's the one, Great Ormond Street, yes. And the doctor there told her straight away that I've got cerebral palsy. Of course Mum didn't know what it was at that time, and she was shocked because--, she hadn't married my dad by then, the dad I've got now, but in the months that--, during that time she met my dad and they got married. I was about two and a half by then, and they got married, and Mum said they told her then, "Don't keep her. Put her in a home. She's never going to amount to anything. She's going to be a cabbage or suchlike." And my mum said, "No way in this world is my daughter going to be a cabbage. I'm going to treat her and look after her." And she did, taught me to read, write. I was reading the News of the World at five years old, so that's how good my education was at home. Without my mum I wouldn't be as good as I am today really, I suppose, you know. But they were good parents, and my father brought me up well, and after Brenda was born my mum used to give me exercises. They had one of these dining room tables that you pull the leaves out, and she used to make me--, got mats to put on the table. Every day I exercised and Mum went, "You're going to walk. You're going to walk." And I did. So she was brilliant. My dad used to help me, take me up the hospital every day to make sure I had the treatment I needed.

Q: Amazing.

A: Yeah. That was good.

Q: How many months pregnant was your mother when that incident happened?

A: Must have been about six to eight, I should think, yeah. It was near enough--, near time. I was born in the October but I think I should have been--, I should have gone on to November, December, I think, because she said she thought I was going to be a Christmas baby. But this happening, obviously--, but I said, "Did I move my arms and that, you know, fingers and everything?" "Yeah, just not--, you weren't ready to come at that time." But obviously it happens now, doesn't it, children are born prematurely and everything. So yeah.

Q: Wow. It must have been so scary for her.

A: Yeah. My mother was a saint. I was a stubborn child, I tell you. I didn't want anybody to do anything for me. But when I got older she did complain to my father how stubborn I was and he said, "I can't say nothing to you. You wanted her to be independent and do her own way. Now she is, you're complaining. So you can't change it. It's you all over again" [laughs].

Q: So once you'd moved into your flat here at Calder Court, what support were you getting in terms of money and things like that?

A: My parents. Nobody helped me financially till--, oh, as I said, I was doing a little bit of jobs for a while. Then when I--, obviously I was down--, my parents lived then in Eastbourne, so obviously I couldn't get there. I was still walking. But I had a little invalid car, I don't know if you know--, not ones that are now, like little Noddies, we called them, and I used to drive one of those, and I used to take that down really. But we used to take--, Mum did the voluntary work for the old people, and I used to take her round to different--, she used to give me money to pay for the petrol and take her to these different people to--, like Meals on Wheels, but it wasn't a van then. She used to go round, if they needed the Meals on Wheels, like an interview, you know. So I did that until I came here. And then when I came here I didn't know anybody. I hated it here, I hated it, and nobody I knew. My parents were down there. My sister Brenda then had moved to Spain, so I had nobody. So I thought I've got to do something. So I asked around and they told me about the Scope in Geneva Road, and I asked about a social worker, and they said they'd try and get me in there, but I hated that too--, sorry, the education side of it was--, I'm not blaming the people that were there. Their cerebral palsy was a lot worse than mine. Some of them were deaf, blind and mentally handicapped as well, so my standard of conversation was--, and I just said to the manager then, "I'm sorry but I can't take this. It's not my…" He said, "I can see it isn't. Stay a bit longer. We'll get you jobs doing things here." I said, "But I've got to be able to communicate. I can't just sit here working. I see they're all happy in their own way, and I'm really pleased about that for them, but it's not helping me. I want to make friends and so forth." And I'm afraid the only way I did, and I don't think this is going to be nice for your--, and I thought, I'm going to the pub. I did like a drink even in those days. But I thought to myself, I'll get a book--, because I read a lot, even then, I read a lot. I thought, I'll get a book. I thought, I can go to the pub, "Can I have half a shandy please?" And take the book and read it, sit there. At least I can watch people going by, and if they happen to come up and chat, which they did, I made friends that way. But people in the block that I got friendly with then, so life became a lot better, yeah.

Q: Excellent. When did you first become aware of the personal budget?

A: Yes, that's when I met Ann McFarlane. I was over at this--, Surbiton health centre, which it is now, used to be a hospital, and it had x-ray places then, and I had to go for an x-ray. And I'd had to get the morning off work to go, and then I thought, how am I going to get to work after that, I'm going to be late, oh no. And I'm sitting there and I must have looked really down because Ann McFarlane came

over and said, “Whatever’s wrong, Kay? You look so distressed.” I said, “I’m just fed up, Ann, fed up to the teeth.” She said, “Why?” I said, “You know, I don’t have help.” I said, “I’m always late.” And I said, “And then the taxi’s always late, and I’m losing money at work. I’m working like a trooper, but,” I said, “I’m not getting anywhere. I’m late and they take the money off me because I’m late, which they’ve got a right to do in a way. They’re not in there for--, it’s not a day centre.” So she said, “Let me think about it, Kay.” Then she must have gone and done what she had to do at the hospital, and I’d come out as well and I was just going home, she said, “Kay, hang on a moment.” So I said, “What’s up?” She said, “Me and some friends are starting up a scheme to get our own staff.” And at that time it was called--, it wasn’t called a personal budget then. I can’t think what it was called then. It wasn’t called a personal budget. But she said, “Why don’t you join us?” I said, “What does it entail? Does it need money, because I haven’t got none?” [Laughs] “No, no, just come down and see what we’ve got to say,” which I did, and then there was five or six of us then. Yeah, it’s a great idea, I like that, you advertise for staff to come. If they get on with you, you do what you have to do. And then I was a lot better than I am now. I could still walk. Although I used a chair outside on the street, I could still walk around the house and so forth. So yes, and when I see what happened, it’s been the change in my life, I tell you, the best thing that’s ever happened to me really in a way, because it--, well, rather than--, I can have who I want to work for me or not have someone I don’t want work for me, and they can come when I want them to be there. And that helped. I never was late for work after that, because I could say, “Look, I need you to an hour earlier than--, because I’ve got to get there as well,” and they did. That was--, I’m trying to think--, I’ve been on the scheme from the very beginning, so it must have been more than 25 years, I’m sure. Ann McFarlane might know the date more than I would, I’m afraid.

Q: That’s okay. Where was it that you were working at that point?

A: Well, then I worked at the poppy factory for a while, you know, for the, you know, Remembrance Day. And then I had a social worker then, who was very good to me, and she said, “Would you like a better paid job?” I said, “Yeah.” I started working for HSBC Bank, which is good, but it’s strange. When I first went, the first day, I went to Tolworth branch, which is just up the road from here, but the girls were very strange, because they didn’t know how to talk to me. I felt that very strange because I’m a friendly person, I’ll talk to anybody, and they wouldn’t speak to me. And I said to them, “Excuse me, have I done anything to upset you?” She said, “I’m scared of you.” Well, one girl said, “I’m scared that we’ll upset you.” And I said, “I’m just like you. I just have to sit in a chair.” So she said, “Well…” Anyway, every time I went to sneeze or get a pen, they were there, they’d do it for me. I said, “I’m supposed to be working. I can do that. It’s only my walking that I can’t do, you know, otherwise I’m okay. My brain is working fine.” And it still went on like this for many, many months. Then one day I had this man come in, who--, I had a lodger at that time. A man came in, who I knew was my lodger’s boss, and he knew me very well and he went, “Oh, look who’s here, the pisshead”--, excuse me, sorry.

Q: It’s fine [laughs].

A: And I said, “Oh, stop it. I’m in a bank. You can’t talk to me like that.” And he said, “She is, honestly. She’s a right--, she’s good fun, a good laugh. And don’t treat her like you are.” Because I’d already told him earlier that I’m finding it hard to cope. And then after that, fine. They said, “Do you let him talk to you like that?” I said, “Yeah, he’s my flatmate’s boss. He always talks to me like that, and I can give as good as I get.” So it all went well then. It only got--, when I’d been there about nine or ten years, I had a manager that could not cope with my disability, which I’d had before in the past, and he took me one day--, oh, it was about the time when we were changing from HSBC to Midland Bank, they changed their name, and the manager of the branch--, by then I was in Kingston. He came and he said, “Kay”--, he’d been out all day visiting clients, and the main people at, as it was then, Midland Bank said, “We might close this one down. We need you to go work in the banks themselves.

Would you be able to?" I said, "Yes, if I can get there. You won't let me walk inside the building because of the customers." I said, "I've got to be able to get my chair--, you want me to use a chair indoors then I need space. I've got to be able to--, if there's a lift I've got to go up and down. I've got to have a lift." And they said, "Oh." And they gave me a number of branches I could go to that would probably be suitable, and I said, "When do you want me to go to them?" "Oh, this week. Go to a different branch each week to see how you'd cope." For the first day I'd been out all day. I'd gone to--, not Sutton, Richmond. So I didn't get back until about before closing time, and the manager was back by then, and one of the girls said--, because they called them by their first names then. I think his name was Norman--, said, "Oh, Norman wants to see you." I said, "Why?" "He's in a foul mood, Kay. You'd better be careful." So I went to see him. I said, "I hear you want to see me, Norman." "Where have you been all day?" So I said, "To another branch to see if I could get my chair in." "Oh, this isn't good enough, you know." So I said, "Excuse me, Norman. I was told by head office to go to this branch. I've got to go to one every day." "Going every day this week?" "Well, that's what I've been told to do. If you don't believe me, please phone up the man and find out for yourself." And he said, "Alright, I will." I said, "Fine, no problem." And then he kept saying, "I'm not happy with this, I'm not happy with this." So I said, "Excuse me, Norman, have you got a problem with me? Is it my disability?" And he went all red. He said, "Well, as it happens, yes, I don't like you working with me." I said, "Why? I've not done anything to you. Am I doing my job alright?" "Yeah, I suppose so. Not as quick as the others but I suppose so." So I said, "Well, nobody else has complained. The staff--, the girls, I get on well with the girls." I said, "Okay, I can't reach some things, but if I need some files they might be at the top, I'll get the girls to reach them down for me." And I said, "I don't need help going to the toilet or anything like that." He said--, and then I said, "To tell you the truth, Norman, shall I tell you what it is? You're embarrassed, aren't you, in my presence? So that's your problem, isn't it?" Not answering. He said, "All I know is I want you out of my branch." So I said, "What?" "I'm going to get you out of my branch. Why do you think they're getting rid of you?" I said, "As far as I know they're not getting rid of me. They're moving me on. And as it happens, Norman, if you feel that way, I'll be happy to leave the branch as well." And this is like near closing time, the customers have gone and the girls were clearing up. You have to cash the money up and get the cheques--, all the work you have to do behind the scenes. And the deputy manager, who was a rugby player and a good friend of mine, he was just about to go, and he heard our conversation, and he was so disgusted, he went behind this wall, and Norman left and he said, "Kay." "Oh, hello Harry, what are you here for?" "I couldn't help it, I heard the conversation. How could he talk to you like that?" I said, "Some people are like that. I've grown up with it all my life. It's nothing new, but in his position I don't think he should have spoken like that because he was a manager. You don't talk to any staff like that." He said, "No, you don't. I'm going to report it." I said, "Oh, don't report it." I said, "He's not worth--, I'm not going to lower myself to his standards. Leave it alone." I said, "They're going to move me on anyway." So they moved into the branch first in Kingston--, because I was in Kingston but in the main one, in the main sales there, and there was one right near the market, opposite the county hall. It's a restaurant now but it used to be a small branch, so I went to work in there. And then after a few months after then they moved him there. I thought, oh, I don't believe this, so I'll have to leave, get away. And they sent me to Richmond, which I loved, but I couldn't get into the toilets--, the chair in the lift. You got in the lift, it was wall to wall and door to door, and I thought to myself, that's going to be hard work. "So what [inaudible 0:26:47] we give you quarter of an hour to go down in Debenham's in Richmond, the branch of Debenham's at the end of the road, because they've got a big disabled toilet in there." So I said, "Yeah, but it's going to take me more than 15 minutes. If the customers are using the lift, I can't--, and if the customers are using the toilet…" So he said, "Alright, we'll give you half an hour." So every time I wanted to go to the toilet I had to leave the branch, even in the winter when it was raining or snowing, and go down to the toilets, which are about six or eight shops away, to go to the--, and I thought, this is ridiculous, I can't take this--, I stayed there 18 months. Then I said, "I'm sorry but, you know, it's getting where"--, oh, the girls there wanted air conditioning and I'm allergic to air conditioning. I said, "I can't stay there with the air conditioning. It's making me ill." He said, "I wondered why you were

taking so many days off." I said, "Well, I never did before. It's because the air--, I lose my voice." So I had to be moved and I went to Sutton. There the manager was wonderful. The girls there were wonderful. I loved working there, but the distance from way over here--, Sutton's quite a way, so I had to get a cab to there. I was there for three years and then they said that they were changing again, we were back to HSBC then, and they said, "Okay, we want you to know selling." And I said, "Oh, I don't know about that." I loved my customers. Most of them--, in Richmond most of them were elderly, and you've got to try and get the money off them and get them to buy products. I said, "I'm sorry, not me at all." "Just try it for a few months." I knew that it was going to be old people that had money, and they want to come and then they'd talk about Charlie, their cat or their dog, you know. And I said, "I'm sorry, I can't talk about that. I've got to try and get your money off you." "What?" "Well, we're thinking have you got house insurance? Have you got life insurance? Have you got this? You haven't got a car. Would you like…?" And they were looking at me and saying, "I don't like this." "Sorry, Mrs Brown," whatever their names were, "It's my job. I've got to." "No, we're going to speak about this." So I said, "Okay." Anyway, in the end they said, "We'll send you up to London to train as a buyer there." And I said, "No." I said, "It takes me an hour to get to Sutton. I'm never going to be able to travel up to London and back every day. I'll be shattered. Don't forget I've got cerebral palsy. As I'm getting older I'm going to get weaker, then when am I going to be able to do that?" So they said, "Well, what do you want to do then?" I said, "I'll have to give the work up. Have you got any other job I can do locally?" "No, that's what we want you to do." I said, "Well, I'm sorry, I can't do that. No way can I." So they said, "Well, do you want to take redundancy or early retirement?" So I said, "What is the most money?" So they said it was redundancy, so that's what I've taken. So I got the money I needed and gave up work unfortunately. By that time I'd got married again and happy for quite a while. Oh, I became pregnant again with my--, in the months before my husband died, I became pregnant again, but my son lived for a little while, but he was killed by a bus. I lived in London then.

Q: Oh, I'm sorry.

A: So I was back on my own again. Then I was on the top floor, as I said, but then they told me they'd got--, I wanted a two bedroom because my last husband I had--, he's a dear friend now. When he was dying he said, "You're going to be lonely, Kay, but why don't you get yourself a computer?" I said, "I don't know how to use a computer. How do you start?" He said, "Look, if I buy you one, will you try it?" which I did. Now I wouldn't be without it. I know more than he does now [laughs].

Q: Amazing.

A: Yep.

Q: When you were working, did that have an impact on the amount of money you received through the independent living scheme?

A: Yeah, it did, obviously it did for a while, yeah. But to get there I had travel expenses, you know. But there was a scheme that did travelling to work and you had so much towards your fare, so I got that to pay for my taxis there as well. But it wasn't easy. Although I must admit, I did--, I'm so glad that I had a personal budget then. Without it I don't know what I would have done. It's been a godsend, it really has, not only to me. Many people I'm sure feel the same way. When you're an independent person and you want to do your own thing and you've still got all your faculties, obviously you want to lead as normal life as possible. But don't forget in those times, like I said in that letter to you, I'd been doing a lot of charity work for people, you know, that I wanted to help going on the scheme. Also I worked for the MS Society, voluntary worker, helping them and that. Still at the moment I'm still there as the treasurer. We've got a meeting tonight in fact to see what's going to be done ahead. So I do that as well.

Q: You mentioned before when we were in touch about campaigns that you've been involved with in Kingston. Can you tell me a little bit about that?

A: Yes, it was when the council wanted to put the money up. And at that time I was manager of the group to with KCIL--, oh, what do they call it now, the group and that, we used to talk about what needs doing and I used to chair it. And so Rosemary, who was the CIO of the KCIL then, said to me, "We're doing this campaign. Will you join us?" "Oh yeah, it's going to affect me. Yeah, of course I will, yeah." Then she said, "Why don't you speak at the chambers to do with the council?" I mean, "What? Oh no. Oh no, no, no, no, no. No, I'm not that way inclined." So she said, "Oh, go on, Kay." I said, "But Ann McFarlane is--, she's a much better speaker. That's part of her job. She knows how to speak to people." I said, "I'm going to get tongue tied and I'm not going to be able to say words I really want to say." "Oh Kay, you will. Write out a speech and let me read it and see." So I said, "Okay." Well, I read it out and she said, "Kay, it's great." I said, "But if I say it out loud I'm going to get upset, I know, because I know it's going to affect so many people." So she said something--, words like, "Have you been in a wheelchair one day? How would you like it if someone had to come in just to clean your teeth or wipe your bottom? Or make you a drink? If you didn't have nobody there you wouldn't be able to drink, which is like it--, how would you like a stranger to come into your home and bring in your--, you know, losing your personality sometimes. They've taken over your home. It's your home, but because you need these things done you've got all these strangers coming in to do it for you. So how would you like that?" And that was integrated into the speech. I know if I said that in front of people I'd started crying. I know it--, because although I can speak, when I'm upset or I'm angry, my vocal cords tighten up like this and the words don't come out. And I thought, I'm going to choke myself up, I know I am. And the first time I did it, Ann McFarlane thought she was going to be doing it and Rosemary said no. She said, "Ann, you're strong and you can say these things. Kay's got the emotion and she will show how much it's important." And I said, "Yeah, I'll cry my eyes out" [laughter]. She says, "No, we want you to do it, Kay." So I said, "Okay." Well, I did it fine. I mean, I did show emotion. I knew I would. And I thought, I'll show myself up. But they all clapped, all the councillors clapped and said how great I am and that. Because I knew my voice was going. I kept having to--, to get the words out, but I did it in the end. And we had to--, one day we were--, it was pouring with rain, outside the council chambers, umbrellas up, soaking wet, chanting, you know, "We want our rights" [laughs], stuff like that. And one of the disabled girls that was with us then, she's a baroness now. I can't think of her name.

Q: Oh, Jane Campbell?

A: Yes, that's it, yes, Jane. And she said to me--, we were walking across the bridges one--, this was one summer. "How about you coming? We're going to chain ourselves to the railings and stuff like that." I went, "Oh no, I don't think so. That's not me at all, no." She said, "We're all going." So I said, "I'll come but I'm not chaining myself to the railings." But they did, we all did so much. But see my plaques on the wall?

Q: Oh wow, yeah.

A: And then KCIL put me forward to get an award for the Soroptomist women, business women, a group. They give awards to people in the borough, or any other borough, who've done so well for that borough. And that's the one at the top.

Q: Oh amazing. Congratulations.

A: Yeah.

Q: What campaign do you think was the most successful of the ones that you were involved with?

A: The first time we won and they didn't put it up very much. The latest one was terrible. They wanted me to go--, as I say, I didn't do much for KCIL then, but when it came--, they wanted to put our percentage up to 100 percent, and I said, you know, "That's awful. Some people can't afford to pay permanently." Now I couldn't, definitely not. And a lady I was friendly with, who's on the MS Society with me as well, she said her friend had taken people there to hear what the councils have got to say, "Are you going to come, Kay?" I said, "Yeah." Well, I shouted: "You're not listening to us, are you? We're back to square one 20 odd years ago. We fought then. You just don't listen. There's still people here that still need their teeth cleaned by strangers and so forth, but you just don't care." And people clapped for that as well. And there's a young man, he's an Indian man. I'm sorry, I don't remember names very well now.

Q: That's fine.

A: He does a lot for KCIL as well. And he was explaining the same things what I was--, and I said, "This young man still says the same things that we were saying all those years ago, and where's it got us? We're still saying the same things. People are not getting the help and the money they need. We're not asking for the crown jewels. We just want to live independently as best we can." But it didn't do us any good, we didn't win. They did charge us 100 percent. So I don't know. I sometimes think that, if only they could sit in a wheelchair for a week without getting help, they might think a bit better, or if they had somebody in their family that was disabled in some way. It's different for me because I can talk, like Ann, we've got our mouths and we can shout out, but there's people that are blind, deaf and dumb, they can't speak for themselves. We've got a young man downstairs, I call him Little John but he's big really, but he's got cerebral palsy and he was in a home all his life until about 15 years ago, when they were letting people out the homes, and he told me--, he can't speak but he's got a ball with letters on it, but he pointed to them. He said he'd been in a home all his life, and when he moved here he shut his front door, because they'd always locked him in his room all his life and now that he's free he didn't want the door shut. So, you know, people were complaining about that. And I said, "Well, if he's been shut up every night of his life, well, what can--, he can't speak. Sometimes he can say, "Kay, Kay," and I know he's calling me. "What's the matter, John?" Come down and I can--, people keep on throwing things at him, you know, saying that he's silly, because the poor man dribbles, but he hasn't got the swallowing power in his throat, which is to do with cerebral palsy. So I'm lucky that way, you know. I feel for people like John because they can't shout for help or do anything to protect themselves. That's wrong, you know, and I still fight for that, people like him that need--, I must admit, he's got a carer now. Although she works for the council, she's very, very good for him. You know, they're supposed to only be there for 15 minutes every time they go there now, but she stays and she cooks a meal for him and that's really nice. [Sirens] Sorry about that. I think that's the fire brigade or the ambulance.

Q: Yeah. Can you talk me through what care you receive at the moment? What's a typical day for you in terms of the support you get?

A: What--, do you want me to tell you what money I get?

Q: Oh no, no, no, but do you have people come in a couple of times a day?

A: Well, when I got my PB and they said that I could get them from KCIL, but I thought I'd rather do it on my own and see what happens, so I put cards in the window, postcards, and I put down 'disabled lady needs help, blah, blah, blah,' and they'd ring me up for a telephone interview. But if I

didn't like the way they'd spoken to me, I'd say, "It's gone already," things like this. Because some people phone up and say, "I want to know what's wrong with you first?" You don't say that. When you go for a job you don't--, I thought, well that's--, two or three people--, well, more than three people phoned up and said that first, and I thought, no, you're not going to work for me [laughs]. I had another lady that come to work for me, I thought she was ever so nice, and I said I needed somebody for Sunday. That time I was walking and I just wanted help in the bath, so somebody there in case I slipped. And I thought we got on well, she helped me out and she said, "I'll see you next Sunday." But she never turned up. So obviously I'd got her phone number so I phoned up and her daughter answered, and so I said, "Why is--, your mum's supposed to be here today. Why didn't she turn up?" "Oh Kay, I'm ever so sorry. Mum's not coming again." So I said, "Why? Did I upset her?" "Not you personally but your disability. It made her cry, you were struggling so much." And I thought, weird woman [laughs]. So I said, "Oh, no need to worry. I've done it all my life. It doesn't really worry me. I only need your mum there to make sure I'm dry properly and to see that I get out the bath safely." But she didn't like me struggling so hard, so that--, you get people working for you like that. So now I've got four different people working for me. One does shopping for me sometimes, so that's five. And what I've done, they all come, apart from one, from the cards in the shop windows, a window in Wilkinson's in Kingston. I had some lovely people come from there [laughs]. And what happens, they come in the morning about 7.30am, and by then I've got myself out of bed but I'm not in the chair properly. I'm not strong enough to get back into the chair. But I put--, this chair tips at an angle and I'm safe in there, so I come out here, open the curtains, take my tablets already laid out from the night before and empty the water from the kettle ready for them when they come. Then I wait for them to turn up, and then first thing they do, they help me into the chair first. They don't have to lift me. I've got all things that I can--, a block of wood against the wall I put my feet on. They're just there to hitch me onto the--, getting further back. Then they put the footrest down for me and put my feet back on that, and I get myself back into the chair properly, and then they can come out. I had to have a--, because although I can get out of bed, I can't get back in bed, so I have to have a Kylie on the bed, which is an incontinence type sheet, for urine, and they take that off the bed. It gets washed every day, and they do that and then they make a coffee. I allow them to have a coffee as well. To me it's friendly. And they say, "Do you want breakfast?" Sometimes--, like today I only had toast, but other days I have a cooked breakfast or egg on toast or something like this. Then they wash the plate up and they make the bed, and they get my towels--, because I don't like damp towels on me, I have to have them warm, so they put them in the tumble dryer to warm them and then they get me onto the--, I go to the toilet, clean my teeth, then I get into the shower. They're there--, they're not doing it--, they're there for me. I shower myself. I wash my hair myself as well if I need it washed, and they come in to help me dry, put me back into the chair and get dressed. I used to get dressed in the bedroom but since I got worse I've got a bar in the bathroom that's high enough and a shower seat, so they put towels on the seat and I get dressed. So I can hold onto the bar while they help me get dressed. Once I'm dressed they--, in the meantime they've made my bed and put things out that I need. Done that and then they come help me--, Brenda, like I say--, she'll say, "Your hair's a tangle. I'm going to give it a good brush." So she gives it a good brush. I style it and she puts my lacquer on and perfume, and they cream my hands for me and stuff. I do my makeup but they--, then she says, "Do you want any hoovering?" I said, "No, it was done yesterday, it's okay." Tidied up the place, what needs doing. That's the morning. And then sometimes--, like if it's a Monday, but not yesterday because it was a bank holiday, another one comes and she takes me out to pay my bills, get my money out of the cash point, pay my bills and we do a bit of shopping, and then she'll come back--, or they might prepare me a meal ready, because I don't have anybody come to cook for me. I have a company called Oak House Foods, I have them deliver once a fortnight. And the girl that comes on Wednesday, she does five hours for me, so she does the same thing in the mornings but she helps me with my paperwork. I do it all but she does the writing up. I tell her what to put, and then if I want it on computer I can do it all on the computer, people's wages for the week and so forth, you know. But they get paid monthly, so I have it all on the thing and then I print it out so it's ready, so at the end of the month they sign for it

and so forth. At night time a lady comes, she's new and she's fantastic. She's brilliant, she really is. She comes about 10pm, but she'll get the bed ready for me to get into. She'll get my tablets out ready what I need for the morning, and anything that needs doing round the flat. "Oh, I've done this [inaudible 0:49:19]. Is that alright?" "Yeah, that's fine, lovely, thank you." And she said, "Time for drinkey poos." So we sit and have a drink together [laughs], and then she helps me to bed, puts the chair on charge if it needs it and then goes off. And I have another one comes the next day. They alternate. If anyone--, like Kim, who does my Tuesday and Wednesday and Saturday--, Wednesday and Thursday and Saturday, she's on holiday for ten days, but the other girls can cover her. I don't get a new one in. And if they're away she'll cover for them, so it all works out really well.

Q: Excellent, yeah. Sounds busy [laughs].

A: Yeah. And other than that, if I want to go to the cinema--, I must admit, one of my PAs is my ex husband, my last ex husband, but we're good friends now, and I got friendly with his wife. She's my cleaner, in fact, his wife now. But he's my carer. Because he knows me so well, I don't have to struggle so much when he's around because he's strong. He lifts me up, you know, like this, and we go the cinema together, the three of us, if I want to go to a concert, which--, I'm a rock chick. I like rock and roll. So I've got a group that I--, they call me their groupie, and I go with one of them to see them. They drive me there. Because I've got a car, a Motability, which is due for renewal in October, but this one's seven years now so it needs changing anyway. I didn't know whether I'd still be able to have one after my age, but as I don't drive they say it's alright so I thought carry on. So I want to go down--, my family live in Eastbourne--, well, my younger sister does, Jill, with her children. She comes up here, but she's got a son who's autistic, and although he loves Auntie Kay, she can't come without her husband, because he needs controlling whilst she's driving, you see.

Q: I'm just going to pause it just for a second. [Recording paused] Okay, so could you tell me a little bit more about the awards that you've won for the work you've done in the community in Kingston?

A: Well, years ago I was--, a group of women called the Soroptomists asked KCIL whether they could recommend anybody who'd done so much in the borough.

[Recording paused]

Q: Sorry Kay, so can I ask you that again about the awards that you've won in the local community?

A: Well, the first one I got is when I was--, I went to KCIL quite often, and these Soroptomist ladies asked KCIL if there was anybody in their members who'd done a lot more work for the council or for them. And Rosemary, who was the CEO at the time, put me forward. "She cares about people. If she knows they're not well she rings them up and she goes round to see them, and if there's any campaigning to do she's always there. And she's on the access committee," which was accessing the borough, you know, ramps and steps and stuff what I had to find needs doing. So they asked me what would I like to do. I gave them what I was doing at that time. The access committee would like--, you know the pavement in the borough, you know the roadway, we were trying to--, it's all over the place now but they weren't then--, wanted ramps to go up and down buildings, ramps to go up and down steps and stuff like this, and I was on the committee quite strongly about that. But I've always been independent and wanted to get about. It's what we're doing. So they came, like you are now, telling me what kind of thing I was doing, and went through my life story, the same thing, and they said, "We're going to have a reception and we want you to come to it." And the women who were on this committee, they were going to vote for who they wanted to win. And I did, I won. I was quite

shocked. So yes, I got the plaque. They gave me a speech and I had to give a speech back saying, "Thank you ladies for…" And I said, "Thank you KCIL for recommending me. I'll do my best to carry on as best I can in the future, as long as my disability allows me to." Yeah, went for that. And then the local mayor wanted to know about people in the borough who'd done things for other disabled people in other groups and on charity work, and KCIL again recommended me, and I won then and I got the plate--, I got a plate, silver plate with my name and the mayor's name on at the time, Royal Borough of Kingston mayor at the time, with my name on, for the work I did then. And then that mayor, who I got on very well with, spoke to the Mayor of London about it. They wanted me to go up to London, but unfortunately that time was when 9/11 happened. And I was going up with one of the staff from KCIL, Dave, he's a rocker like me and we were very good friends and we were going up to London with one of the volunteers there as well, Pat. And we never made it because they stopped the cars from coming through, so I missed out on getting the Mayor of London's speech--, it was Ken Livingstone at the time. But because I missed it, Ken Livingstone wrote to me when it had all died down a little bit and said I could still get the plaque. Unfortunately you won't have the reception, drinks and food and everybody there, but we'll send you the plaque anyway. That's when I got the one from London.

Q: Amazing. So that's when you got the Mayor's Community Award, is that that one?

A: It's that, the London one, the silver one.

Q: Oh sorry, yeah, yeah, the Mayor of London one.

A: Yeah, that's the Mayor of London, that one. I'm sure it was Ken Livingstone then.

Q: Yes, it is, yeah.

A: Because you know 9/11, the bombing in London.

Q: Yeah, 7/7.

A: Oh yeah, but it was all going on then, wasn't it? That day traffic couldn't go through. I couldn't get to the reception there, so we had to turn back, and I said, "Oh, I don't want you to turn back." Dave said, "Let's go down to the seaside instead." So we went down [laughs], which is really lovely as well. But a couple of months later the Mayor of London contacted me and said I can still have my plague, "But I'm sorry you missed the reception." But he said, "We've heard that you do a lot of work for the borough and you must be proud of that." I didn't think nothing of it really. It was just something I did [laughs]. But he said, "I want to wish you all the best for the future, and please accept this plaque. All my best wishes." So that was nice.

Q: Very nice.

A: Yeah.

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

A: The one that comes from the borough itself. I think so. Although it was nice that the Mayor of London did it--, I got to know Ken Livingstone quite well after that, but it was still good because it's the people in my own borough where I lived, which was quite--, I'm quite proud of that, I must admit, yeah. But it was nice that the Soroptomist ladies put me forward too, and KCIL, but I didn't know them. I mean, I knew them a lot afterwards but I didn't know them then. I didn't even know what they stood for at the time, I must admit.

Q: So could you tell me your thoughts about the current state of the disability support system in Kingston?

A: Well, you're asking me the state of--, financially it's reasonable, I manage, but I've had to fight for what I want, with the help of a friend. I don't think the council realise how much disabled people need certain things. You know, my shoes, when I was walking, I got through a pair of shoes a week. I had to buy new shoes every week because I'd wear them out, the way I walked. And if you're disabled and you need incontinence things or certain medicines, you've still got to pay for them. You don't get them all free. Dentist, you know, I've to pay. It's hard. And when I do try to get a bit more, you know, they just don't really understand. Always complaining about money for disabled people. We're not asking for the crown jewels. We just want to be able to live as normal as everybody else does, as best as everybody else does, to be able to live and not just exist. It's alright existing if you're--, but people who've got good mental ability, they want to be able to live, not just exist. I think that's what's wrong with it all, you know. I want to be able to go out and enjoy myself like anybody else does, and I can't go on my own. I've got to have a carer with me, and of course they've got to be paid. They don't understand that kind of thing. I can't go anywhere without a PA or a carer. [Phone ringing] [Recording paused]

Q: So I just wanted to ask you one final question, Kay, which is what do you hope to see happen in the future when it comes to supporting people with disabilities to live independently in the community?

A: I'd like them all to have the amount of money they need to lead a peaceful and helpful life, so they can live independently. I hate having to worry about the next penny. I'm sure I'm not the only one in my situation. And as I'm getting older, my disability's getting weaker, of course, and I don't want to go into a home. I do like to be here, but I will need a lot more money. But will the local council give us more? I don't really know. And the rate they are at the moment, I can't see it happening. And although they say you've got family, my two sisters have got their own families. They can't live their lives--, I don't expect them to--, I'll be a burden to them as well. Of course if I want something really badly, new coat or something, they'd get it, but they can't expect to put up with it the rest of my life. It wouldn't be fair to them, would it? Well, I don't think so anyway. So I'd like it to be that--, I don't want to be rich. I just want to live comfortably and happy, the best I can be with my disability, and I don't think that's asking for too much, in my opinion. And keep the PAs I've got now because they're all so wonderful.

Q: Excellent. Thank you so much. Is there anything else you wanted to talk about that I haven't asked you about?

A: Hmm, married to my first husband and being pregnant, that was a major thing for me because I had to get--, obviously I was still disabled. I was walking about with one stick. And people used to say I walked like a drunk but with a walking stick. And life was hard. But I lived in London, needs Lambs Castle then, Waterloo, and I got in the morning, went to see to my husband, because he couldn't manage then, and I had a like--, because we lived in an old house, I had to make sure--, and we didn't have central heating then. We had coal fires, so I had to clear the grate out, clean it with the thing and light the fire, get the flat warm before Michael got up, and I had to lift him. He was nearly six foot and I'm only 4'11" [laughs]. But I was able to manage it. I got him into the chair. If he wanted to go to the toilet, I'd get him on the hoist, take him over to the toilet, things like that. Life was hard but I was happy, really happy. And I think I've been lucky because I had a good home life when I was younger. My mum did make me a strong person, and a positive person probably [laughs]. I'm not quite sure about that one. But because of it I've been able to lead the life the best I wanted to, you know, really.

I've been a lucky one. At least I've still got my faculties and able to speak up for myself. So that's all I can say about it.

Q: Thank you so much.

A: You're really welcome.

Q: I will stop the interview there then.

[End of recording 1:04:05]