

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Wodynska
Given name	Renny
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Q: This is an oral history interview with Renny Wodynska by Jen Kavanagh on Wednesday 21st June 2017. The interview is taking place at Renny's home in Stratford Upon Avon as part of Kingston Centre for Independent Living's Fighting for our Rights project. So thank you very much for being interviewed. Please could you state your full name?

A: It's Renny Wodynska.

Q: And what is your date of birth.

A: [REMOVED] 1958.

Q: And whereabouts were you born?

A: In Birmingham.

Q: And what are your parent's names?

A: They were called Wladyslaw, my dad, and Czeslawa, my mum.

Q: Could you spell those for me please?

A: Ah, W-L-A-D-Y-S-L-A-W, and C-Z-E-S-L-A-W-A.

Q: And whereabouts were they from?

A: They were both from Poland.

Q: And what were your parent's professions?

A: Well they were agricultural workers really, peasants I guess, caught up in the war and they came over after the war in the '50s, and then I was born a year later [both laugh].

Q: Okay, lovely. So whereabouts did you go to school?

A: I went to school in Birmingham. I was very, very lucky because I got a scholarship to go to the best school in Birmingham, which was a real privilege, but you don't realise it at that age [laughs]! So I did that. I then did the one year Birmingham University, I did Latin with Italian, realised after a year it wasn't for me, although I loved Latin for seven years at school. And then I went to the Polytechnic of Wales and did something really different, communication studies, which had sociology and psychology, and that ignited me, I realised that's what I wanted to do and I went into social work from there.

Q: What made you choose that course? What attracted you to that?

A: It was fluke really I think. I'd never been exposed to ology's at school because I was at a very traditional academic school. But I had volunteered when I was 15 down the road at a sheltered housing scheme for people that had visual impairments, and I remember after the first day I went home at five and I said to my mum and dad, "Can I stay late?" And I would stay 'til ten 'o clock at night, I loved it. And I always volunteered from that age after that, so I got my first job before I even qualified as a social worker, as a social work assistant because I actually went along to this day centre to offer my services as a volunteer. This was the old days. They said, "Would you like to come for an interview next week? We're interviewing for a social work assistant," and I never looked back.

Q: Amazing.

A: Yeah [laughs].

Q: So is that the first job that you did once you finished your education?

A: After I did my--, yes, after I did my degree and so on, yes, that's right [laughs].

Q: So could you talk me through what you did sort of at that point and when you joined Kingston Council?

A: Well my first job therefore was in Mid Glamorgan social services in Pontypridd in the valleys working as a social work assistant with older people and disabled people, and I was just always drawn to that area of work, it always really interested me. So we moved to London when my partner finished his degree, as he was from London, and I got a job at Hammersmith and Fulham social services. I was a centre worker and I got upgraded to deputy manager of Askew Road day centre, and that was back in the early '80s. Really loved that job, but I knew I wanted to qualify as a social worker at that point so I had some experience with working in one of their dementia residential homes and then I went to Surrey University and did a postgraduate course, and in the meantime I'd done some studying at Goldsmith's University in London in the evening, so I only needed to do a one year course, and Kingston was my first job post qualification.

Q: So what was it you were studying in terms of your postgrad qualification?

A: Social work.

Q: Oh okay, yeah, yeah, oh I see. What was that like, doing that qualification?

A: Really enjoyed it. I had a placement, my first placement was in a hospital working with all sorts of people with health issues, disabilities, I loved it. It was really my bag. You had to have a placement working

with children, which I did, and teenagers, it just wasn't for me. It's interesting what you're drawn to isn't it? But throughout all my career that's always been my bag really, working with sort of health issues, disability issues, or issues that affect older people.

Q: So when you joined Kingston Council, what was your job title at that time?

A: Social worker.

Q: Oh okay, and so what did that job entail?

A: I worked with various, well, various health issues, it was called the general health team. So I can clearly remember some of my early cases 'cause I did keep in touch with a few people when I left London. I was privileged, I felt I have made a difference, which I was so happy about! I remember working with parents of children who had acquired disabilities when they were young because the services, if you had a child who was disabled in the '40s or '50s, very, very different expectations to now. Through to working in a multi disciplinary team at Surbiton Hospital, which I loved. I worked a lot with people with dementia, and one of the things I did was run a monthly support group for people looking after people with dementia, and obviously the knowledge wasn't quite as advanced as it is now. Whilst we're still learning, it wasn't as advanced then, and just providing support. So it was a really interesting job 'cause you could do lots of different things. I remember I worked with a fabulous young woman who had the misfortune to acquire, well, she became a wheelchair user through a freak accident and just helped her settle back in the community after being in hospital. And again, the services, this was in the late '80s, the services had moved on from the '60s, the '70s, but I suppose thinking back it was still quite a disablist world. I'm not saying it isn't now but it was even more so then. The legislation that is here today wasn't there then, but yeah, so lots of different work with people aged 18 through to probably then in their eighties, very varied.

Q: Who made up the team of people at that time when you first joined?

A: We had, well it was a very small close knit team and it was colleagues who were also trained social workers or social work assistants. Very, very close team 'cause some of us still keep in touch, I mean 30 years later, they'll always be close friends, so, professional background. The team, as I say, was purely social workers and social work assistants. I can't remember how but for some reason, as I mentioned, I was working also with Surbiton Hospital, and that was a mixed team with occupational therapists I worked with very closely. We had physio working with the nurses very closely, working with the matron very closely, and that was a fabulous multi disciplinary team. You knew you were doing a good job because you had time to work with people in a person centred way.

Q: Yeah, it makes sense.

A: Yeah it did, it does, definitely.

Q: So can you sort of talk me through where things were at in terms of the independent living scheme when you were there and when you first encountered that?

A: Well the first I knew anything about it, my recollection, and bear in mind this is a long time ago, I remember my boss who was Jane Bearman was the team, I think she was by then team manager, and Jenny Webb who was assistant director told me about it and they asked me whether I would be interested in being the first facilitator of that scheme because two disabled women in Kingston had through, I think it was the Kingston Association of Disabled People, approached social services to say things could be very different to how they are. Rather than home care staff we haven't appointed coming in at times we haven't particularly chosen, and also being very task oriented, the vision was we can have a different way of being here. So I was so lucky 'cause I was in the right place at the right time, I really was very, very lucky. So the first steps for that were then me working, as I recollect, with Ann and Jane, to look at how we set the

scheme up. I mean what I do remember is there was an incredible lack of bureaucracy. We just sort of picked up on the idea, they were in the lead, I had to listen hard and get things going and support them in making the vision happen. So yeah, it was something very, very, very different at that time. As far as I can recollect I think there was already a scheme in place in Greenwich and Hampshire, but we were amongst the first in the country. My recollection is also the director, Roy Taylor, was very supportive of it. I think Jenny Webb really made it happen but Roy Taylor was very supportive as well and very committed to making things happen. So there was, it was an exciting time, it was really interesting and really exciting, and something very different, a very different way of working.

Q: Do you remember how you felt when it was first presented to you as an idea?

A: Well I was very interested. I always like some new challenges, and it was, yeah, it was going to be something, you know, a bit scary as well for me because would I live up to the expectations of these two fantastic women as well? 'Cause I could see from the first meeting, I can't remember if I knew them before or not. I have a feeling I didn't know Ann and Jane particularly if at all before, but I knew as soon as I met them, you know, they were women that made it happen so they had a fairly clear vision of where they wanted to get to so it was really, I wanted to be there working in the right way and not tread on their toes in any way if I can put it like that. So it was really, I suppose say bringing my listening skills, my facilitation skills to the call and discovering those skills as well really.

Q: So when you say you were asked to be one of the first people to facilitate that, what does that mean, what does that involve?

A: Well I was the first person, I was the facilitator until I left London basically. Well, what that meant is they were the first two people, so it was working with them to look at everything I recollect from working on job descriptions, setting up--, adverts, interviews, supporting them then to manage those staff that they had. And then gradually, as I recollect, fairly soon, that took off. So then it was expanding that work with other people to engage with other people to support the message to get out, because everyone had a different level of skills. Some were more skilled than others, and it was helping people to find out what they wanted as well, what they were looking for, 'cause it was very person centred. So everybody's view of what they were looking for in their PA was very different, so how could we capture that? How could we successfully advertise? Where would we recruit? How would we interview? What would be my role in supporting them? I mean certainly when I was there, my recollection is up to the point I left I think I was present at all the interviews. But one of the things that developed fairly soon, I remember it was a PAUG we called it [laughs], personal assistant user group, because you realised the power was not in me giving the message, it was people that were actually using the service to say, look, we're here, we're making it happen. This is what we did to solve this problem or that problem, shared job descriptions, it really was about making the service led by the people. And that was a change because I think, I do genuinely think the philosophy of the general health team was very much to take it from the person's point of view, but somehow that was a step further, that was a step further. 'Cause we hadn't before, we hadn't quite changed services round the individual to that extent before. A key thing also was personal self assessments and shaping, supporting people to identify what their needs were. And I was at the right place at the right time because this is, and I will be political here, this is before austerity. I was able to be in the right place to help people meet their dreams. It was a privilege. I think the traditional service, fantastic as it was, and it was brilliant, some of the best people I've ever worked with have been at Kingston, honestly, they're passion driven. However, not a service quite the same as the PA service. And what we were able to facilitate with that, and that's thanks to Jenny Webb and Roy Taylor I think, was a personal self assessment that was holistic, it did look at the human being. People weren't looking to be institutionalised in their own home, it was living a life. 'Cause I always say as a social worker or managing services, I want to give people a great life, that's what I want, that's what we all aspire to. We can be 18, 58, 108, it doesn't matter, we want to be dreaming, thinking about tomorrow, enjoying life, having fun. It's very difficult to have that if your personal support needs take over and you have to worry about getting to the loo, such basic things, getting to the loo. Well how are you going to put your trousers on or your underwear on, or you know,

how can you have a job when such basic, basic things are difficult? Also we are more than just work, and at that point in the scheme we were able to support people to do everything from go to football matches, go to the pub, go on holiday. People have travelled, I don't know if they still do but you know, some of the postcards I had, oh, so and so and their PA saying, hi Renny, we got here at last! Fabulous! And we take it for granted, we take it for granted, and I still think that is so hard for too many people today. But I think at that point, fabulous, the scheme was helping achieve those ambitions and people were finding their abilities, their dreams and achieving them.

Q: Yeah, absolutely. In terms of the self assessment that you were supporting people to do, how did that work? What were the sort of criteria that they were--,

A: Well, as far as I can remember it was very much driven by the individuals who were getting the PAs, and the first self assessments were shaped very much by Jane and Ann. So it was very much looking at key areas of your life, and I think we took a lot of it on trust that you are the expert in your own world. 'Cause most people, and there are exceptions, but most people don't want someone else to be supporting them for a second more than they need it. But if you need it you need it, and I think it was seeing the individual as the professional in their own world and with their own health issues. And I think the other thing was it was very much, and this was new to me, the social model of disability. So actually we are disabled through society, through attitudes, through the way things are around us, through steps for example. We can achieve so much more if those difficulties can be overcome through the right support. So it was very much with the social model of disability underpinning.

Q: Was there any sort of conflict I suppose internally about how that worked? I mean obviously you said, you know, it was very much about trust between the individuals and them really promoting what they felt their needs were, but within the council was there any sort of uncertainty about how that was working?

A: Well it was a very new model and I do remember that I think I did the first presentations I think I ever did in my career were about that to other colleagues, 'cause it was about spreading that word. Because we hadn't been trained in the social model of disability in the '80s, that was a relatively new concept, to my recollection, and you know, colleagues would have been trained before I was. I was, you know, obviously a young social worker at that time. I don't particularly remember difficulties though because probably I was working with people who had a very can do attitude, and certainly the colleagues I worked with in the general health team, I think there was a lot of support, certainly from management and certainly from a lot of colleagues with this very different way of working.

Q: That's really positive and that seems to be the case that a lot of people said that it was the right people at the right time.

A: Oh, yes, yeah.

Q: So it's really a good thing.

A: Well I think people make, I think individuals make the difference to anything isn't it? If you've got the passion and the drive you'll be committed to making something work, so yeah.

Q: Yeah, absolutely. So it was Ann and Jane who were the first who sort of went through all of this process.

A: Yes, the very first, yes.

Q: Yeah. What sort of obvious changes did you see in terms of what services or provisions or activities that they could access, or just I mean in terms of whether they were living their lives?

A: Well they could just get on with their work. Both very active women, they could travel. Just the difference in thinking, oh, I need to keep asking for help, asking for support, just the difference in your confidence. The ability to organise your life, to be in control, what a difference. 'Cause the does he or she take sugar model was prevalent, and I suspect it still is for some today. But they are fantastic role models for people. They have paved the way for so many people who now go behind them in their footpath because of the work they do, their attitude, they ambitions and their determination. So it has enabled them to get on with life rather than, oh my gosh, I've got to sit in, my home carer hasn't come. I mean can you imagine? You're delivering a lecture, an international lecture, oh, my carer hasn't come. And yet that's what it must have been like until the time that that scheme took off.

Q: So soon after they, like you say, obviously were very strong advocates for the scheme and were really leading the way in terms of showing how it could be a success, what was then the sort of interest within the wider disability community?

A: We're going back a very long time, so my recollection is that we gradually, gradually had through talking about the scheme, the Association of Disabled People was very, very much promoting the scheme, and it was gradually making people realise, there is support for me to do this. Because it would have been a big step for a lot of people. What was very lucky was in that period we didn't have quite as many bureaucratic hurdles to jump over. We sort of ignored a lot of things in the outset, such as is someone employed or self employed? That really, because it was so new it wasn't coming up as an issue there. Also the law wasn't as complex as it is around areas such as sleep ins, the tax, the pensions, so that just wasn't there in those days. So my recollection is we actually after the first two individuals then, Ann and Jane, we gradually had people come on to the scheme with some regularity, 'cause I remember it built up to some regularity, 21, 22 before too long, very, very gradually, and this is where we got the personal assistant's use group set up. I would go and see people and once they were set up and things were running smoothly I would go and see them regularly and just say, "Is everything all right? Any issues that you've got, any concerns?" Because we just sort of got on with it. We didn't look at, we never looked to see problems, we just expected things to work, we didn't look for problems. We didn't do training then of people in any way, but in a way it didn't matter because as I say, if there were concerns that PAUG meeting, which I seem to remember was every month, people would take and share, or I could say, "Oh, speak to so and so, they've had that experience," and it was about that networking and sharing confidence. Some people would need a little bit more support than others, 'cause it was new I think to most people to draw up job descriptions, person specs, we obviously did all that very thoroughly, very properly. But I don't remember any particular problem 'cause we were just very positive about it. You look for problems, you can always find them. I think there's a lot more risk averseness than, the concept of risk wasn't there in those days in the same way that it is now. People that have not come across it will say, "Oh, what about safeguarding, what about this?" We dealt with things as they happened and it worked, it really did work [laughs].

Q: From a sort of finances point of view, I mean I don't know how much you were sort of involved with that but can you sort of talk me through how the financial system worked in terms of the, from applying for your money?

A: You're asking for details I can't remember now after all these years.

Q: That's fine [laughs].

A: It was very basic. The individuals had to keep, at the time I was there, they had to keep the records of what went in and what went out, and I would support them if they needed it. Some people were more confident than others, so everyone at that stage to my recollection had to do their own, but it was fairly straightforward because you didn't have the tax and pension issue. And I do remember some people needed a bit more assistance than others, but then I would see them a bit more often to just support them with that. So gradually, gradually the sort of simple procedures developed, but they were very simple

when I look back, my, they were probably on two sides of A4, you know, when you get documents and documents now. Very, very simple, but that made it work as well.

Q: And was all of the funding coming directly from the council, through social services?

A: As far as I can remember, it was, the main bulk of funding would have been. In those days you probably would have had as well, but I can't particularly recollect this, you would have had as well the independent living fund through the benefits system, and I think that's gone now hasn't it? So that might well have also contributed, but my recollection was the work I was doing with this scheme, it was Kingston Independent Living fund. The other issue for us of course was we were ahead of our time because direct payments were illegal. The privilege I did have, because I do remember I had to go to the houses of parliament, whether it was with Ann McFarlane, I can't remember who else was there. But that was a fantastic privilege, to go there, to lobby to get direct payments in. I think it was Liz Lynne who was the Liberal MP, my recollection is the meeting was with her, it must have been very early '90s, 'cause it became law I think then in, two or three years later in '93, '94, but certainly when these schemes were happening, late '80s, it was illegal, so it was rather exciting. But how fantastic to have been working in a directorate where they were prepared to take those risks, because I just don't think you would get that now, sadly, sadly.

Q: Yeah, I know, it's funny that hearing from both the council staff I've spoke to and from those in receipt of the payments that everyone was [laughs] very much aware that it was essentially a money laundering operation, but that was really the only way to trial for it to work. And the fact that it's a scheme that still exists today is, you know, shows that. I mean you've touched on this a little bit in terms of the people who played a big role in terms of the success of the scheme, but what else do you think it was that made the scheme so successful?

A: Well, I think it came at the right time as well, it was early on. I suppose we were at the cutting edge, we were at the cutting edge. Certainly the fact that we had two of the most able women in Britain in terms of the disability movement, that was paramount, absolutely paramount. But I think second the fact that they had a directorate that was prepared to listen and take on board their views and ideas. Maybe if they'd been [inaudible – 30:44], so it was a lot of the right people at the right time and I piggy backed on that, 'cause that, if all that hadn't been there I wouldn't have been there. So I think it was all of that. It was the willingness to make it work and to reflect on it and to just learn lessons. 'Cause I'm pretty sure reports must have been written, I barely remember that. The things that I really remember, very people oriented, are the people, 'cause I still keep in touch with quite a lot of people even now, 'cause I know it made such a difference to their lives. And it's just the privilege to have been there in the background facilitating it really.

Q: So how did your carer then develop from the work you were doing in social services at that point?

A: Well I've continued working in social care all my career. I went to live in the Midlands afterwards for personal reasons, and I worked in Hereford and Worcester for a long time. And to be honest that was a very big shock when I first moved. I hadn't realised how ahead London and Kingston especially were. I went to Herefordshire and Worcestershire social services, it must have been '93, I think '93 or '94, and I felt I'd stepped back in time with the services that are there. They had a couple of things that were really excellent that stood out in adult social care, but on a personal level I felt I'd really stepped backwards so that was quite a shock. But I stayed there for several years in different roles. I then moved to work in the private sector for four years with a long term healthcare insurance company that was very, very, initially when I joined, very personal centred, fantastic service, but that was acquired by AXA and I knew I wouldn't stay long because their values weren't my values and I'm very value driven. So I then went on to work for a national charity for a few years, set up because of the amount of suicides in farming and the agricultural sector. So that was very interesting because that was working with civil servants and ministers in London and Wales... really, really interesting to work with so many people affected by suicide actually and various organisations support them. I then worked for Bourneville Village Trust for ten years working as the

director of supported housing, which was managing various services. A little bit in the private sector, and I've joined Skills for Care last year and I'm now head of the Midlands area, which is covering West Midlands from Shropshire through to Lincolnshire, up to Nottinghamshire, down to Hereford and Worcester. What's been so interesting is I really feel everything's utterly joined up in my career because one of the work streams is very much to support the employment of PAs, support individual employers, promote direct payments, promote all the things that I was working on [inaudible – 34:30] years ago or so. And I think what's been really disappointing is how little progress there's been. Also what has really struck me is the lack of joined up-ness between commissioners from health and social services. So someone's needs might change, suddenly they're getting a budget from the CCG and not the local authority. That's not joined up. They may have to make PAs redundant to re-employ. There's a lack of knowledge of what a PA is. So we've not done very well at promoting what this incredible role is and how life affirming it is and how different it is. And I suppose what's so disappointing is the fact the bureaucracy, it does put people off with pensions. You've got to obviously give people protection, but my goodness, we have made it complex, the different requirements, employment tribunals and their impact. So I feel as if I've come full circle but even now one of my colleagues last week was saying she'd done a talk at a local authority to the team, one of the teams, the social work teams on the work we do on PAs, etc., and the social workers were saying, "We don't understand what it is. We've been given this task across this particular authority. We haven't been given the skills." And it's quite a shock to hear that, it really makes me realise how Kingston were very, very far reaching, how visionary, how can do they were, and it just shows how difficult it is to change culture to move to a social model of disability. And I totally get it, why people feel they're still institutionalised at home, still having to beg for what really is a human right. And I think what's also disappointing is we were so very, very holistic and now you're right as an individual to be a working person, to contribute to society and have a fulfilled life with leisure time, people you love around you, seeing things, having a great time, that's almost become harder than when it started and that's really bizarre. So it's exposed me to what's going on, certainly in my area. And one of the things we've said as a team, we want to make closer contact with the ULOs, with the user led organisations so we can work more in partnership with them in the Midlands. I've now got a full time and that's one of my objectives with the team this year. So we can pick up where I left off all those years ago where we left off in a funny way, and hopefully drip, drip some of that out. I think there are a lot of committed, passionate people out there, but there's also this culture of risk averseness, which has really affected the growth of this sort of scheme I think.

Q: Have you encountered any other local authorities who have been working in a similar way and have sort of initiated independent living schemes?

A: Well I'm aware there are independent living schemes of some sort all over the country now, it's an objective they have to meet. But I believe they are struggling. The payments that are made to people in order to make the payments to their staff have been compromised I think in some areas, and as I say, we've now got commissioners not working with commissioners. And really the commissioner should be that person who's employing the PA with support, but we've got a whole plethora of people. They weren't actually there as a job to be honest, it's got very sort of retro. But sometimes you wonder whether various roles get in the way, 'cause you just think sometimes if you could sweep them away maybe we'd have change a wee bit quicker.

Q: Yeah, absolutely.

A: Yeah, so our role is to help promote now at Skills for Care, and we will be trying to do that with the work with ULOs in this region now in the Midlands if we can.

Q: In terms of the--, I mean again, you've touched on this to an extent already. So the work that you were doing in sort of '80s and '90s in Kingston, do you feel that that really has had an impact on the work that you have continued to do and particularly what you're doing today?

A: I would still say it's amongst the best things that I've ever done. I know it's had a magnificent impact, only 'cause I happened to be there though, and thank the Lord I seemed to get the right approach with people, facilitating, supporting. But some of the individuals coming on to the scheme were going through difficult times, but I know--, I think what's just so moving to me, and it does move me even now, you know, it's lovely, I do keep in touch with quite a few people 'cause I know I have helped them achieve their dreams. And I don't know that they would have got there quite as quickly. Hopefully they would have got there, but it's sort of a bit, you know, I say old fashioned social work and that sort of almost sounds a bit paternalistic, I don't mean it like that. But when you go into social work, if you've got the vocation you really want to make a difference to people's lives. And a good day is, actually I really did make a difference to that person's life, wow! And I have had a few wow moments. It's as good as it gets really.

Q: Yeah, absolutely. What would you say is your most proud achievement of all the work that you've done?

A: Well I think it is the feedback I've had individually from some of those people, some of whom have passed away now, some of whom, thank goodness haven't. And the fact they still want to keep in touch with me, I've seen the odd person occasionally and I would hope if there are any celebrations to get down to see more people. It makes you feel very humble, proud and humble and privileged is what I generally do feel. It is helping people live the life they want, yeah, definitely.

Q: And in terms of the current state of the disability support system I suppose, what are your sort of main concerns at the moment as to what the future is, particularly independent living I suppose is?

A: Well I would question why has it taken 30 years to move forward like a snail? Unless it has real champions it just won't change enough. You've asked what impact does it have now? I suppose one of the impacts now is I am working, we do work with Skills for Care and I am personally working with some disabled people in the Midlands who are very, very active in this area, very much driving the agenda forward. Very similar to Ann and Jane but they're located here. And I've had the privilege of listening to some of the things that have been happening to them very recently. And I'll be honest, I sat there fuming 'cause I thought, well I used to hear stories like that in the '80s, how on earth is it that we are still replicating such dire practice now across the health and social care system? Change is sluggish and austerity has been an excuse to make cuts, which are affecting people badly. I always remember Jane and Ann talking all those years ago about the fact is, you know, why should you pay to go to the toilet? They're active women, they've contributed more to society than many other people on this planet. Why should they be worried or anyone else? It's something we so take for granted. We are so lucky if we think, oh, I'll go to the loo. Oh, I'm hot, I'll take a jumper off, or I'm cold, I'll put these trousers on. We're so lucky we can just go and do it. To have to be reliant on people who don't want to be doing that job is the worst thing possible. It should not be happening in 2017. So I'm really hopeful that there will be passionate, committed people going forward to drive the agenda. But my worry is I don't really see enough of that happening, 'cause why has it drifted for 30 years?

Q: What changes do you think need to happen in order to better support schemes such as the Independent Living scheme?

A: I think it's difficult because the world is very different. You almost forget what it was like 30 years ago, our frame of reference is very different because safeguarding and risk aversion I think are very strong drivers of decisions that are made now. And they just didn't feature in your thinking. We've almost gone too far the other way, and in some ways we all just take risks by living. You have to take risks, 'cause if you have no risks you're living in this little bubble that is unreal. Somehow we've actually got to promote more the fact that we've got to put those aside to enable people to live the lives they want. I almost feel that we've got to go back to the civil rights movement. Sometimes you feel that change only really happens when people take action. I know I'm being political, I think that's the thing. Politicians, I'm very sorry to say, only seem to respond if you make a noise.

Q: You talked about lobbying to the MP back with Ann at that time. Were you either involved with or at the receiving end of any other campaigns in Kingston?

A: Not that I particularly recollect, this was the main area. There was a lot going on because the work that was going on in terms of lobbying, that led to the changes that have happened in Disability Discrimination Act. I mean I was working with people, a wide range of people, but I know--, I mean I really do remember I think more or less everybody that I worked with because their experiences up to that point, some of those individuals are proud, they told me their stories. The level of discrimination they had by expressing an opinion [laughs], absolutely shocking, the level of discrimination was utterly diabolical. And yet you feel sometimes it's moved, but it hasn't moved that much. So that was really, all of this was happening in the arena of moving towards the disability rights legislation in the '90s, and now you've got the Equality Act of course.

Q: Yeah. Do you, again, I mean it's going back a long time, but do you recall how the media were responding to all of these changes? I mean was the Independent Living scheme picked up much by local press in terms of promoting--,

A: I don't remember that, I don't really remember that. And I suppose I was reading, I was reading papers and articles and tuning into people with the same view. I suppose you tend to stick to your own, so I remember I was reading stuff, for example, by Dr Mike Oliver who was very active in Greenwich as far as I-- , I think he was a lecturer at Greenwich, so, and I think it was through Ann, work that had taken place before this scheme had taken off in Kingston in America from the civil rights movement. So I suppose I was looking to, my influences were from people who'd led the way rather than from poo pooers. So I don't recollect anything other, I suppose I'm drawn to the positive than the negative by nature [laughs].

Q: It's probably a good way to be [laughs], sometimes it's better to ignore them.

A: A bit naïve probably, but it wasn't, that was probably more Jenny Webb and KADP and Roy I think that would have been in charge of that.

Q: Yeah, fair enough. Have you travelled much through your work and seen other schemes around the world?

A: No I haven't.

Q: Yeah, I would be interesting to see how that sort of spread, 'cause obviously there was stuff happening in the US, but yeah.

A: Yes, I suspect Jane would know much more about that.

Q: Well I think that's all of my questions but if there anything else that you wanted to talk about that I've not asked you about?

A: No, I think only that it's the one piece of work I've been involved with, which I probably do cite more than any other for the impact it's made on people's lives. Just such a positive difference. You couldn't but help to be exhilarated working on it, 'cause people were very happy. The difference it has made to people's lives, fantastic. And as I say I do keep in touch with some people now, and I've still got--, I'm not sure, I don't think any have got the same PA but a lot keep in touch with their old PAs as well. I mean it's a different sort of relationship to traditional--,

Q: Yeah, it seems really strong to me.

A: Yeah, it is, it is, 'cause, because of that the network's fantastic.

Q: And what are your sort of plans in terms of your own career? What are you hoping to achieve?

A: Well I'm probably coming to the end of it soon. I'm probably looking to retire in another three years or so to be honest, so looking to make the best of my current role at Skills for Care and really enjoying bringing together all the things I've done, all the varied things I've done, because this is a great job for working on all areas, from helping with attracting the right staff, recruiting staff, retaining staff, a lot around leadership and management, which I'm very interested in, how to role model fantastic behaviour to staff, which helps you with inductions, keeping them, etc. The work is very wide, very different, and you can get involved in lots of different projects. So I'm really enjoying it, it's a great opportunity for me, which is fairly unique 'cause there's only six roles like this in England, so I'm very pleased with it really.

Q: Excellent, cool, well thank you so much, that was really interesting. I will stop the recording there.

[END OF RECORDING – 00:51:46]