

ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Reilly
Given name	Robert
Date of birth	1956
Place of birth	Isleworth, Middlesex
Date of interview	10 May 2017
Length of interview	00:40:41
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Name of interviewers	Zoe Perry, Alisha Ale, Jen Kavanagh
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Q: This is an oral history interview with Robert Reilly by Zoe Perry on Wednesday the 10th of May 2017. Also present is...

AA: Alisha Ale.

JK: Jen Kavanagh.

ZP: The interview is taking place at Kingston Centre for Independent Living's office as part of their Fighting For Our Rights project. So Robert, hello.

RR: Hello.

ZP: Could you please state your full name?

RR: Robert Reilly.

ZP: And your date of birth, please?

RR: [removed] 1956.

ZP: And could you tell me, please, where you were born?

RR: Isleworth.

ZP: And where's that?

RR: Middlesex.

ZP: Middlesex, okay, and did you grow up in Isleworth?

RR: No I grew up in Shepperton in Middlesex.

ZP: And can I ask your parents' names?

RR: Edward and Anne.

ZP: Surnames?

RR: Reilly.

ZP: Erm, and could you tell me what they did as, er, work?

RR: My father was a rigger in the studios, my mother was part-time working, but mainly bringing up ten kids.

ZP: And was that, erm, in Middlesex?

RR: That was in Shepperton in Middlesex, yeah.

ZP: And can you tell me where you went to school?

RR: Thamesmead. Er, do you want all schooling? So secondary education was Thamesmead Secondary Modern in Shepperton. Prior to that, from the age seven until 13, I would have gone to what was--, would now be termed a special school. It was a school for disabled people, run by the Sha--, or funded by the Shaftsbury Society, which was well-known at that time, running residential homes for, what in those days were called, handicapped children, not disabled children.

ZP: And can you tell me a little bit more about that?

RR: That school was a very old medical model, in as much as you--, you were a resident there because of your medical needs, not to gain an education. So although you had classes, it wasn't a State school education level, which meant that by the time I was 13, somebody somewhere was thinking, he needs to be educated somewhere, so they moved me into ordinary school at age 13, which was a bit of a culture shock.

ZP: And when you say ordinary school...?

RR: Mainstream schooling.

ZP: Mainstream. Can you say a little bit more about that school experience?

RR: [Sighs] [Pause] Well it's not something I can remember that well, to be honest. It's just a period of time that I wasn't at home for term time. Erm, I felt very comfortable because I was with other disabled people, whereas once I'd left there and I was pushed into this new environment of mainstream school, I obviously--, I stood out. I was one of two disabled kids in the whole school, so you then began to feel vulnerable, picked on, erm, but in the end, it made you confident. You didn't feel confident when you first went there, but it helped with your confidence as you grew older, how to handle these type of things.

ZP: You mentioned a disability, can you elaborate a bit more about that, please?

RR: Most of the people that were at the residential school I was at had spina bifida, which is what I was born with. There are levels of spina bifida, erm, you could be paralysed from the chest downwards. I'd say at least 50 percent of them were in wheelchairs, were wheelchair users at that time, and there were others

who, to my eyes at that age, I wondered why where they there? I didn't--, I couldn't work out why they were there, but clearly they had some neurological problems, otherwise they wouldn't have been there.

ZP: Did that present any challenges?

RR: The schooling there?

ZP: Hmm-hmm.

RR: Not the schooling, no. No the challenges came later on, when I was in secondary modern, trying to fit in with mainstream schooling.

ZP: You mentioned fitting in with mainstream schooling.

RR: Yeah.

ZP: Is that something that you can talk a little bit more about?

RR: Well by that, I just mean obviously somebody with a physical disability stands out a mile at mainstream school. They were very unenlightened days. Now I think you'd be far more comfortable as a disabled student at school. You'll be more accepted. In those days, the, erm--, the often-used word would be 'crippled' or 'spastic'. It was a very common name for the other kids to throw at you. You would never hear that sort of language these days.

ZP: How old were you when you finished school?

RR: All of my schooling? 17.

ZP: Can you tell me a little bit more of what happened after that?

RR: After that, I became a trainee journalist with a news agency, based at Heathrow, erm, so that involved interviewing people who were arriving at Heathrow. It was a period when there wasn't mass, erm, travel by the likes of us. Travelling by aircraft, in those days, was pretty much reserved for the rich and famous. So if you had a news agency based at Heathrow, you'd have photographers, you'd have reporters on site, and in those days, nearly every day, the lead picture in the tabloids like *The Mirror* or *The Sun* would be of one of these stars arriving at Heathrow. I mean, you don't get it these days, obviously, but--, so I did that for four years and decided it probably wasn't for me. I wasn't as good at it as I'd liked to have been, so I gave that up and changed career, quite--, quite markedly, actually. I then became a bookie for 16 years and that changed because legislation allowed betting shops to stay open on Sundays and in the evenings and actually, I quite liked my cosy little 10 until 5:30 job that I was in, and that's when I thought actually I probably need to get a few more arrows to my bow and learn something else, so I went towards office work. I got offered a job at the Ministry of Agriculture at Tolworth. Did that for four years, got made redundant and went to KADP as a part-time admin assistant, which I was going to do for six months, a year, to fill in and here we are, 17 years later.

ZP: So you mentioned KADP.

RR: That was Kingston Association of Disabled People. That was the former KCIL, before we became incorporated.

ZP: How did you hear about the organisation?

RR: Funny you should say that. I think it was an employment advisor who knew me well, and she said, 'Go along for this interview, you'll get it.' So I did and I did [laughs]. Erm, there were seven or eight of us

and I thought, after the interview, I thought well I won't be getting that. Somebody asked me the question, 'What do you understand about the social model of disability?' and I just looked blank, never heard of it before. I just assumed I wouldn't be getting that. A couple of hours later, I got the phone call to say the job's yours, so I don't know who's pulled strings, but somebody must have.

ZP: [Pause] And how old were you when you joined the organisation?

RR: Good point. Erm, [pause] 44. I guess, yeah, 43, 44.

ZP: You mentioned that you were surprised at landing the role.

RR: Well because I knew very little about disability then. I didn't consider myself to be disabled at that time. I hadn't claimed any disability benefits that actually I later learned I was entitled to claim because I was of the mind set, I'm not disabled. I don't need your help. I'll come back when I do. Some years later, I did. Years later, I looked into and I thought, actually I probably will claim DLA, Disability Living Allowance. I got turned down initially but then on appeal, I was given a higher rate mobility but being turned down initially is nothing, really. I later learned that at least 50 percent of people are initially turned down for DLA, and even to this day with PIP, you still get the same type of figures. PIP is Personal Independence Payment, which has taken over from DLA. So everything I've learned about disability, I've learned in the 17 years I'm here.

ZP: Would you like to say a bit more about what you've learned?

RR: Can we pause a bit? [Pause in recording] So I joined what was then KADP in January 2000 as a part-time admin assistant to the then development director, who was working towards making KADP a centre for independent living, which we weren't. We didn't have that status at that time. Erm, he left the organisation probably 18 months after I started and then the staff who were originally here, slowly, they moved on from positions and as certain staff moved away, I picked up pieces of work to do because somebody had to pick up, er, like the finance part of the job or servicing the board of trustees part of the job, and that just automatically fell into my lap somehow and I accepted it. I suppose it was a challenge and I thought yeah, it helped me to develop, so why would I turn that chance down? Well the more of those pieces of work I picked up, the longer I found myself being in the office. Therefore my role evolved from being a 21 hours a week admin assistant, I was then made a full-time office administrator by the new, erm--, new CEO, who was Mark Moss, who was instrumental in this organisation, first as, erm, somebody who ran what we used to call the ILS, the Independent Living Scheme, which is now the Direct Payment Scheme. He had left that position and gone to work for the British Red Cross, erm, and then when the CEO's position became available, he got wind of it and he came back and joined us as CEO. He was--, he had many impairments but despite that, he had a lot of energy, a lot of drive. He really drove this organisation forward and it was he who took us through becoming a company, so incorporation. At that stage, I almost became his right-hand man on, erm--, on looking after documents that related to incorporation, related to--, or even moving premises. So a bit of history about the premises. We were based in Siddeley House, in Canbury Park Road, in Kingston, with a lot of other voluntary organisations in 2000, at the time I joined. Round about 2004, we were growing--, we outgrew our office there, we had to look for new premises and the premises here at River Reach were the only ground floor premises we could find. However, this was not an office. It was an unused, erm, basically an unused car sales showroom and that was its lease use, as far as the Council were concerned, so we had to get a special licence from the council to convert this unit to an office and we were given a special lease for five years for this office. So I project managed the contractors coming in and fitting this office out because it was literally--, it was a shell. Everything in it now was fitted out by us.

ZP: Where did you receive funding for those changes and for the organisation?

RR: I can't really recall where the funding came from, but my suspicion would be that it came out of our reserves. I don't recall any, erm, strategic funding at all for the actual move or the fitting out of the offices.

ZP: And the association, in general, how did you receive funding?

RR: We--, our main core grant is from Kingston Council, and that was to run the ILS, the Independent Living Scheme, which evolved to the Direct Payment Scheme. So that allowed, also, to pay the salary of the CEO and my own position. There was sufficient in there to be able to cover that. Other posts that we had at that time, would have been funded by organisations like the Big Lottery Fund, as it was then. So we had to go out to other charitable organisations to seek funding for the posts that we wanted in the organisation. There was a--, there was an equalities worker here at one time and I know she was funded by a charity. I can't quite remember the name of the charity.

JK: How many people worked here when you first joined?

RR: Ali, Rosemary, Eddie, Karen, five others. Five people when I joined.

JK: Who were they?

RR: Ali Kashmiri, who you will have heard of. He was the access and information officer. Karen Fenwick, she was the finance worker. Rosemary Green ran the ILS. Anne Freda was her assistant and Eddie was the--, the--, I'm just trying to think what his surname is. I should now it [laughs]. He was the development director, but I can't recall what his surname is now. So yeah, it was five, and a few volunteers, regular volunteers. A married couple used to come in, erm, once every week, do work in the office. Er, we probably had a--, er, I think probably John Raitt had joined at that time, as bookkeeper. If it wasn't in 2000, it was certainly soon after he joined. So it was a small team at that time, but big enough for us to think about moving our--, in fact, erm, the equalities officer, she had joined at that time that we were at Sidley House and I think that was the point at which we said, right the office isn't big enough. We're going to have to find other premises. That wasn't easy to find premises in Kingston Borough, so we were pretty lucky to find this and be able to retain it.

ZP: Just to backtrack slightly, you mentioned Mark Moss driving the organisation forward. Can you say a little bit more about the aims of Kingston Association for Disabled People?

RR: [Inaudible 0:20:46] [Pause in recording] So there would have been a time in the mid-2000s when we would have employed a black and ethnic minority worker at the organisation, who was funded by City Bridge. Erm, at various times, we've had access officers, er, but not for probably a decade now, erm, which coincided also with the time when Kingston Council stopped having an access officer themselves, so very little on access has actually been done in the last decade in this borough. We're now looking at--, with the board, I'm looking at forming a new role within the organisation for access. We'll be looking at access audits, erm, forming an access sub-committee group to look at all aspects of accessibility in the borough, including transport, which I think is--, that's very important for independence. Erm, historically, Kingston Council used to give a pot of money to KCIL, Kingston Centre for Independent Living, to run a holiday grant scheme for disabled people, whereby they could, erm, apply for an amount of money to support them with the costs of going on holiday. RBK ceased that scheme in March 2016 and shortly afterwards, the board of trustees of KCIL made a decision that actually that was a service too important to let drop, so they made a decision to fund it ourselves, from our reserves; and that began in June 2016. At that time, we also decided that there was a need for grants for equip--, for disability-related equipment. So they set aside a similar amount of money from our reserves, to run this grant for equipment, which has been pretty successful. We've helped half a dozen people in the last nine months to purchase equipment that they otherwise wouldn't have been able to get through the local authority. Just recently, we've discussed that there's probably a need for grants for people to attending training, educational courses, training courses, so we've set up a small, erm, scheme for that as well, which is only just getting underway now, so I don't know--, we can't judge yet the success or otherwise of that.

ZP: You've mentioned a lot of projects that involve helping people with independence and that's part of the name of the Kingston Centre for Independent Living when it changed from the Kingston Association for Disabled People. Can you tell me a bit more about the evolution that led to that change?

RR: Well I think a lot of it's around language and positivity. [Pause] It's that evolution from handicapped to disabled to then not talking about the medical model of disability, talking about independence. So you've evolved from that person is handicapped, to with the right support, that person's independent, so you become far more part of society.

ZP: How did the organisation evolve to meet those aims?

RR: So there wasn't that much evolution from KADP to KCIL, other than us becoming an incorporated body. Our aims remained the same, they always were the same, to support independence, to campaign for independent lives. Erm, if anything, some of our members and service users might have thought that the change to KCIL made us too corporate and we were no longer what they saw as the friendly local organisation that they could drop into. There's an argument there, that perhaps we became too professional.

JK: Were there any other sort of responses from the community to the name change?

RR: Not that I can recall, no. It may have confused some people. What centre of independent living means to the majority of people out there, I don't know. I think unless you actually work within the disability area, you wouldn't really know what a centre of independent living is and I think, even now, there are people within KCIL who would prefer that we were named, or we had a name which included 'disabled' in the name, or something positive about disability rather than centre for independent living. I mean, we have been mistaken as a--, as a housing association type organisation before. You'd get people knocking on the door, saying 'Oh I'm homeless, can you help me get a home?' because they believe independent living is associated to housing. So I can see that, er--, I can see people's reasoning behind wanting the organisation to be named something including 'disabled' in the name.

JK: How would the organisation define what independent living means? What does that mean to KCIL?

RR: Living without the need for somebody to be looking after you, I guess. Living with the me--, being given the means to look after yourself, being given the opportunity to be independent, run your life the way you want it, not the way the medics think it should be run or the way the council may think it should be run, by sending in home care at any given time of day when actually that might not be convenient for you; or giving you the type of care support that you need. So independence really means supporting you to live the way you want, rather than the way some medical minded people might think you should be doing or medical minded people putting limitations on what you--, on what they think you can do. There shouldn't be any limits. You know, you're independent, you should be able to do everything everybody else can do. The opportunities should be there.

JK: What does that mean in terms of the support that is offered by KCIL?

RR: So overall, my role within the organisation, I see it really as supporting the people who serve the disabled people in the borough and that's mainly the direct payments team. There are four people within that team, and they administer for direct payments users, helping with paperwork, helping with recruitment, answering lots of queries, reassuring people, so I'm here really to help them do that job. There are--, there are also support brokers in the organisation as well as a business development manager and, of course, the CEO who oversees everything.

ZP: Was the CEO involved with the, erm, organisation becoming incorporated? Is that something you can talk about?

RR: The CEO at that time, Mark Moss, he was certainly heavily involved in the organisation becoming incorporated. I think it was his idea that he put to the board of trustees and they agreed it, so at the time, it would have been the CEO and the chair of the board of trustees who would have worked on incorporation, the idea of incorporation, but I don't think that incorporation necessarily changed anything for the users of the organisation. The organisation's aim and support remained the same. It was merely an administrative change, as far as I could see.

ZP: Do you think that type of support will continue in the future?

RR: Yeah, absolutely, and it will probably grow and needs be, that we will probably have to grow beyond the borders of Kingston Borough and perhaps join with other local disability organisations in other boroughs, erm, to become bigger in order to access funding for our projects because councils are withdrawing more and more from giving disability organisations the type of financial support they need to run their services.

JK: What do you think are the biggest challenges ahead for the disability sector?

RR: [Sighs] For KCIL in particular, it's growing and finding premises to grow and getting an income for core costs, to cover core costs, to cover staffing. Erm, we've got to find a way, I think, of joining forces with other organisations to strengthen, to increase our income, to be able to provide more services. We've got to get larger, rather than standing still. Funding from the councils is not going to suddenly increase again, so more and more is going to be put on the shoulders of organisations like ours to provide services.

ZP: So you were talking about, erm, [pause]--, so you were talking about the biggest challenges faced by KCIL.

RR: Our biggest challenges are going to be financing the organisation to continue it. Finding funding for it to continue, erm, and we may have to look at joining forces with other disability organisations, erm, going across boroughs. I mean, we're constituted at the moment for services in and around the Borough of Kingston. In the future, that may have to change. We may have to go further afield and, er, join forces with other disability organisations in perhaps Richmond, Wandsworth, Merton, or the areas that border us, erm, so that we bolster finances together so that we are strong enough and big enough to be able to apply for funding and for projects which will come up in the future. There's going to be strength in numbers, I think, because otherwise small organisations, I think, will just get swallowed up. There's always the danger that small local organisations will get swallowed up by one of the national organisations, who have got lots of resources and who would like to take on things like the direct payment service that we run.

ZP: Have you been involved, in the past, with those funding streams, organising them?

RR: Yeah. Just recently we won the contract to run the direct payment service in the borough. So there was a time when we received a grant from Kingston Council to run the direct payment service. They then went over to commissioning those services and we had to tender to continue to run the service that we had previously been grant funded for, and I think we beat off nine other organisations, many of them large national organisations, in order to get the contract for this area.

ZP: Was that a proud moment?

RR: Very, yeah. Yeah, everybody worked really hard. The CEO worked her socks off to, er, ensure that happened. The board came together very well and supported the CEO really well. Yeah, everybody pulled together for that, so it was a moment of relief.

ZP: Have there been comparable moments in the past, in the history of the organisation?

RR: Not really because we'd been grant funded up until then, erm, so the grant just continued year--, I think probably on a three-year basis. It would just get renewed, so that was the first time we had a competitive tender, which was a big change for an organisation like this.

ZP: Would you mind just repeating that? There was a bit of noise outside [laughs].

RR: That was the first time we had--, we had to go for a competitive tender, which was a big change for an organisation like this.

ZP: Were there any other changes that you've been proud of interested in, particularly?

RR: Not that I can think of at the moment.

JK: What would you say is your proudest achievement while you've been working here?

RR: Probably project managing that move from Sidley House to here. Yeah, it went very smoothly. Erm, pretty much any time that I could change a contract that we've got, be it on a photocopier, on our telephony system, and it starts saving the organisation money, then you think yeah, that's what I'm here for. You know, I am here to get the best deal for us for what we need. So it's always good moment when you see a budget sheet and you can see, from one year to the next, that costs have gone down on something that you're responsible for looking after. I suppose it's helping the organisation to survive financially, although the grant--, administering the grants is quite satisfying because you often get postcards, letters from recipients of holiday grants, saying 'Thank you very much. Without your help, we wouldn't have been able to afford to go on this holiday,' and how much they benefited from it. Then you think, yeah, we're doing our job. I think moments like that, make you pretty proud, yeah.

ZP: Is there anything else that you'd like to share with us, that we haven't discussed?

JK: That seems like a nice place to stop.

RR: Yeah.

ZP: Okay, thank you very much.

End of recording [00:40:41]