

## ORAL HISTORY RECORDING TRANSCRIPT

### 'Fighting for our Rights' project

<b>Surname</b>	Tong
<b>Given name</b>	George
<b>Date of birth</b>	1965
<b>Place of birth</b>	Surbiton, Surrey
<b>Date of interview</b>	13 June 2017
<b>Length of interview</b>	01:10:31
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<b>Name of interviewers</b>	Ijeoma Aniyeloye, Jen Kavanagh
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Q1: This is an oral history interview with George Tong, by Ijeoma Aniyeloye on Tuesday the 13<sup>th</sup> of June 2017. Also present is?

Q2: Jen Kavanagh.

Q1: The interview is taking place at Hollyfield House in Surbiton as part of the Kingston Centre for Independent Livings, Fighting for our Rights project. Sir, can you please state your full name?

A: George Tong.

Q1: And what is your date of birth?

A: [REMOVED] 1965.

Q1: And whereabouts were you born?

A: I was born in number 6 South Bank, Surbiton, about 300 yards up the road that way.

Q1: Okay, and what were or are your parents' names?

A: My parents are Colin Tong and Eileen Tong and they live in Tolworth.

Q1: What were their professions?

A: My dad worked in retail, worked in shops and stores, and my mum worked as a PA secretary administrator.

Q1: Okay, where did you go to school?

A: I went to school at Tolworth Infants, St Matthew's and Southborough Boys' School.

Q1: What was your experience like going to school?

A: Ooh, [laughs], I can't remember relishing much of it, it was tricky, I was dyslexic so the infants school was largely a social experience for me, and one of starting to grasp quite how difficult learning things was going to be. Junior school was a bit of a right off because they went through various experimental education systems while I was there, which they subsequently abandoned, leaving me ill prepared for what happened next. Southborough Boys' School was an eye opening experience, it was an old fashioned secondary modern so it was really a kind of technical school, it was a tough place to be, lots of life lessons were learnt very quickly at Southborough, or you didn't survive it. But in the midst of all that I was seen by an educational psychologist when I was about nine or ten, who managed-- helped by my teacher at the time to come up with a diagnosis of dyslexia, so at the time I was able to access a form of special education in Kingston, which meant being taken out of school to go to a different, a separate school called the Reading Centre where we were given two to one, or one to one sessions with teachers specialising in helping children with dyslexia to learn to read and write. And my understanding of the world and letters and words changed dramatically during that period of time. So yeah, I went from really struggling to do anything in school, to doing okay and starting the catch up by the time I got around to O levels and the like, yeah.

Q1: Can you tell us a bit about your experience working as a volunteer during your school days?

A: Well it was fundamentally due to my year head at the time who probably took--, much to his credit was able to make suggestions and thoughts about what he thought maybe people might like to do and benefit from doing without actually patronising us to the point where we felt like we didn't want to do it because it was his idea. And I think he must have seen something in me that he felt would maybe respond very positively to being in an environment where I could be supportive to people who perhaps were less able than I was. So he directed me to come down to Bedelsford School which coincidentally was on the same site as the Reading Centre so it felt like going home in many regards, and I finally got to find out what all those funny noises were that were going on downstairs when I was upstairs trying to learn how to read. And I was there at a very opportune moment for me because that it was being run at the time by a chap called Tom McMillan who was the acting headmaster, he was incredibly welcoming to me, accepted me warts and all for whatever it was he felt I had to offer, and basically just threw me in the deep end and I got on with it. It was, yeah, probably a transformative moment in my life, although at the time I had absolutely no idea that's what it was, but looking back on it it absolutely was.

Q2: And what did your volunteering role sort of involve?

A: Well funnily enough it was helping someone else to read [all laugh], which yeah, there's a kind of sweet irony there about the fact that I went to Bedelsford to do that, having only learnt how to do it upstairs from Bedelsford, but I used to do one to one with a boy called Paul Harvey Goodman who was, he must have been about a year older than me at the time and he was finding reading quite difficult and so I would sit with him as he ploughed through his reading book and he would try really hard to distract me and get me to do anything other than what I was there to do. And sometimes we did a bit of reading, but most of the time [laughs] we mucked about and enjoyed ourselves.

Q1: Can you explain how your time at Bedelsford impacted, you know, on your understanding of disability as a whole?

A: I suppose in a way I had a completely unacademic introduction to that, there was a strange culture at Bedelsford, it was a school, but it was a school where there was a large part of what was going on was medical, there was a school nurse who probably rivalled the headmaster for authority in terms of what happened and when it happened and how it happened. There was a physio department and everybody had physio, the physio department was very well resourced, there was three fully qualified professional

physiotherapists there, so you know, that would be a luxury of resources in anyone's estimation. And although I didn't know it then, I've spoken to some of the teachers and Mr McMillan in particular and there was always a bit of a dilemma in terms of the teaching staff who would wrestle over whether or not because so many of the children who were at Bedelsford had limited life spans and were not likely to live to adulthood, was their role to try to make their experience as enjoyable and rich and diverse as possible whilst maybe not leading them towards any academic qualifications. Or should they be at school, because that was what they were employed to do, at all costs, regardless of what that might mean for the pupils who were there. It's really interesting to talk to some of the pupils who are still contemporaries of mine about what that meant for them in the long run, because there were many children, I guess most of the classes, probably half of the children in the classes wouldn't have lived to adulthood, so in that regard it's very hard to argue that you should be giving someone a hard time about trying to aspire to a CSE in typing if they're not going to live to be 17 or 18 years old. But the children who did reach adulthood and are adults now and are probably not necessarily looking back on the academic achievements that they managed with great joy because they're quite limited in their employment opportunities, I think they might have a very different perspective on that, yeah, so you were asking me about disability. That this was 1984, '83, probably '82 when I started as a volunteer, you would be as likely to have heard the word handicapped then as disabled or disability, and very few people would have known that there was any difference in the meaning of the words. The children, the pupils, the teachers would have been very comfortable with the word handicapped, would have used the words interchangeably, if they used them at all, and they wouldn't have been very--, certainly when I first started there, there wouldn't have been very much of a notion of disabled people or disability or disability rights, there wasn't a discussion about whether those children should have been in special education or in mainstream education. That did happen while I was there and it did start to become more of a, a more apparent debate and discussion and I think a lot of the pupils became aware of that as well at the time I was there, but certainly when I started I was oblivious to it if that was going on. And there was no kind of formal introduction to the work there as a volunteer, and I've subsequently become employed there and I didn't have any formal introduction, there was no disability awareness training, there was no disability to be aware of, it was just children with special needs in a special education environment. It taught me an enormous amount about discrimination, about separating people, about not affording people the opportunity to experience the same choices and rights as every other person was experiencing, simply because they had a physical disability. But it was more lessons that I was learning through watching those pupils grow up, being in contact with them as they grew up, talking to them as they wrestled with those issues themselves and thought about the difference between maybe their siblings' experience and their own, their own attitudes towards their own impairments, how it affected them and how many it did or didn't disadvantage them. Generally speaking, I would say most of the pupils there absolutely loved being there, most of the time, there were one or two who found it stifling sometimes, quite restrictive, but they would have been there from the age of two to the age of 17, and they would have been in a class of about 12 people often the same people for the whole of that time. So not just in terms of the education they were afforded, but in terms of the social experience, they were incredibly close knit, they knew each other inside-out and back to front by the time I was in contact with them when they were 14 or 15 years old and it was like a family, it was very much like a family. There was people who were helping them and supporting them who would have been involved with their intimate personal care, as well as being around them in a school environment, so there were all kinds of different relationships in the school and you became very close to the people that you were supporting and I'm still in contact with many of the people that I worked with then. It didn't feel like work, I wasn't getting paid for it to start with, in fact I don't think I got paid for it, for more than a year I was signing on when I left school, but when I started to get paid for it nobody kind of took me aside and said, "You're going to need to start being more professional now George," it was still, you know, just carry on in much the same way as you were. And talking to some of those people now, we return to that and we talk about whether that was a good thing or a bad thing, I've got my reservations because obviously I've spent nearly 35 years in social care, so I'm very aware of all kinds of different training expectations, supervision, induction, everything that you could imagine that wasn't present when I started doing that kind of work so I've got my reservations, but most of the pupils that I worked with then say to me, with absolute commitment, they wouldn't have had it any other way. My view is we probably got lucky, in some senses.

Q1: How old were you when you left school?

A: I left school when I was 18 I think, I stayed on to do A levels, but at that time I'd been volunteering for probably over a year at Bedelsford and for longer than that at the holiday clubs in the summer which catered for a similar group of children. So yeah, that's when I left school.

Q1: So when you left school, did you just continue, you know, with Bedelsford or did you have a job another job?

A: No, I carried on, I started signing on so I was unemployed, and my voluntary work went from one afternoon a week to five days a week as a volunteer, until a vacancy came up at Bedelsford which I applied for, I think that was probably a period of about six months or more between leaving school and being unemployed and then getting the chance to apply for a job at Bedelsford.

Q2: And what was the job that you applied for?

A: It was described as a welfare assistant at the time, it might be differently monikered now or some way described differently but that was how--, the carers, for want of a better phrase, the people who provided the personal care to the children were described as welfare assistants, we were employed by the education authority so that it might be slightly different from social care in the way that that role was regarded and how we were employed and graded. We helped out in the classrooms as well, so probably quite akin to a teaching assistant now, there would be aspects of that, as well as providing personal care and helping out on transport and being involved in the playground duties and being involved at mealtimes and lunchtimes and all sorts of those kind of aspects of the job.

Q1: How long did you stay at Bedelsford?

A: I suppose all told I was involved there for around about four years, but the job I probably only did for about 18 months, before I left to go and work in social care.

Q1: When did you join the Centre for the Handicapped as it was called then?

A: That's a really good question, it's so long ago, I think even my pension provider has forgotten 'cause they keep putting the wrong date on it. I think it was probably--, no, I know, I was 21, so [laughs] that's a long time ago now, got to do some maths in my head [counting to self], 1987 I think.

Q1: And what was your role at the centre?

A: That job was described as a technical instructor.

Q1: And what did that role, what did it entail [all laugh]?

A: I'd love to say it involved technically instructing people but it didn't seem to do much of that, I think that job title related to the kind of industrial rehabilitation model of impairment, so the idea was that we had a massive woodwork shop there, we had lots of different light industrial machinery, and people with acquired disabilities, for the most part people with acquired disabilities would be referred to us for a period of rehabilitation with a view to try to get them into employment, so this might be the room swap.

[Break in recording].

A: We would have had referrals from a wide range of places, often from hospitals, usually from occupational therapists working in the community, doctors, sometimes nursing services as well, often social

workers would have referred people to us and the expectation of that model of care would have been that you would have had people with you for a short period of time, alongside the kind of opportunity to learn new skills, would have been the chance to have spent time coming out of the home, socialising with other people, but there was very much an expectation at that time that it should be a short-term intervention, and that our objective would be to rehabilitate people in order to return to work. By the time I had started there, the whole employment situation within Kingston had changed out of all recognition, and all of those kind of light industrial manufacturing jobs had either gone or were going at a very rapid rate of knots. So, the actual opportunities for people to learn skills that they could put into effect in a workplace, was diminishing quite rapidly. And I don't think that the model that Kingston Social Services had at the time was able to keep up with that change, so through that period of time there was a kind of a rapid change really around people staying much longer and the service becoming much more of a social outlet for people who were otherwise going to be quite isolated. There would have been opportunities to do broad rehabilitation work and we were still trying to always keep an eye on trying to find opportunities for people to be occupied in mainstream activities, but back in 1987 we were a long way away from quite understanding how much the landscape had changed around us and how as a result the service would need to change a lot, from a very medical model, to something quite different. They wouldn't have been aware at the time it was a medical model, because nobody would have been aware of the social model to contrast it to, but it was managed by... no, it was led by occupational therapists, there would have been a senior OT and I think at that time there would have been as many as four full-time occupational therapists an OTA and a part time OT so it was a really OT orientated model of rehabilitation. And the technical instructors were the unqualified people who knew how to use saws and machinery and trying to get people to get their hands dirty and go and make bird boxes and stuff.

Q1: When did the name change to Crescent Resource Centre?

A: Goodness me, that's a really good question. I could probably find out, the only way I'd know would be to look at old paperwork to see when we started changing the headings on all of our letters, I would--, it remained the Centre for the Handicapped for quite a long time after I first worked there, I think we probably would have been in the early '90s, maybe the late 1980s, but more likely the early 1990s when the discussion started. And it was a gradual process, it started with a discussion about the terminology, and whether--, there was a big restructure which ended the kind of OT predominant model, and I think the thinking around the name, and the appropriateness of the name started at the same time. So at a guess I'd say probably around about 1990. And interestingly, and hopefully you'll get the chance to speak to people from different perspectives about this, there was real concern about the impact that that name would have on the way that the service was viewed by everybody except the people who worked and used the service, who were completely comfortable with the terminology. Could not understand the debate around the meaning of handicapped and why that might be viewed as a pejorative term, and were quite resentful that anybody would suggest that they knew better than them about what their centre should be called. And in a way I suppose that's where one of the interesting dynamics occurred, that we had worked really hard to engage people who had previously been very passive recipients of a service, to take more of a role in how it was run, and we kind of made a classic mistake somewhere along the line of continually saying, "This is your service, how do you want it run?" And people said, "Well it is our service and the way we want it run is for you not to change our name, so there was a really strong dynamic there that the people who used the service had no problem with it, they'd known it as that for a long time, they felt that it was a fair description, they weren't insulted by the terminology. We had an election, we had a few choices of different names and the resounding choice that came back was they'd prefer to keep it the Centre for the Handicapped, so having made one mistake we then compounded it by a second, by having a choice presented to people and then when they chose, telling them that's the wrong choice, and imposing a decision upon them. So from the outside I knew well enough and I knew some of the people who were exasperated by why the people who used the service didn't understand that that terminology was rooted in a very unhelpful definition of disability. But equally the people who used the service and liked it, were starting to feel some sense of self-determination around we can make some changes, we can have more say in the way this service is run, and the one thing that they were really strongly of a mind about was that

they liked the name the way it was. So it was quite a painful process, I don't think we--, we didn't lose anybody as a result, but there was some heated debates at times. And one of the interesting things, and one of the things that I love most about working at the Crescent, was that it contained an incredibly diverse group of people, with all sorts of different strengths and weaknesses, some people who could convince you that after a good five minutes of being berated by them, that this guy was not blue, it was in fact sky blue pink, you know, and you would go away believing it, just because they were expert back room lawyers who could, you know, force their way into your head by sheer strength of will. And there were other people for instance the gentleman who used to be the sub-editor at the *Daily Telegraph*, proofreading the newspaper, who would go and find a dictionary and find the original origin of the word handicapped and would prove without any doubt that the definition that was being proposed by the disability movement was in fact not true, it served a purpose but it actually wasn't true. And that was really interesting because there was always a good discussion, there was always a good debate, and in the end people had to accept that actually it really doesn't matter what the truth is about the original etymology of the word handicapped, if people don't like it anymore that's the point, not whether it originated from people going around with their cap in their hand begging, which actually isn't the case, that isn't where the word came from. But that's a moot point, it's just a learning experience for all concerned, the name changed to the--, from the Centre for the Handicapped to the Crescent Resource Centre.

Q2: And what services was the centre offering at that time?

A: Has it changed do you mean from the kind of industrial rehab model?

Q2: Yeah.

A: Well maybe one of the ways to kind of understand what was going on that was different was we had people described as day-care officers who replaced the occupational therapists, and they would have had a role that involved providing personal care, but also they would have been keyworkers, they would have been responsible for organising activities, and they would have had a role in that key working to look at whether or not there were things that we could be supporting people to do, to enable them to be living more independent lives and more engaged in mainstream activities. So it wasn't to say that we didn't have any role at all in employment, we did successfully support some people into employment after they'd acquired disabilities and we supported some people with congenital impairments and, you know, lifelong disabilities to get work as well. But it was, I think it changed the way that we depicted ourselves, we didn't say that that was the main reason that we existed, and part of that was born out of the reality that that was extraordinarily hard to achieve. You know, it was the 1980s, there wasn't an awful lot of employment for anyone at that time, just let alone people that were looking for employment who maybe had a very changed set of skills to the ones that they'd previously had. So that was still part of what we were doing, but we were doing a more social, more educational activities as well.

Q1: How long were you with the Crescent?

A: Well I suppose all told, from 1987 I was there until six years ago, [laughs], so here we go, more maths, '87 to 2011, '12, 26, 27 years, something like that.

Q1: When did you first become aware of Kingston Association for Disabled People?

A: Well I became aware of it when it was Kingston Association for [sic] Disabled People.

Q1: Oh okay.

A: So that might date it, I'm not sure. I remember them going through some fairly painful meetings and debates about the change of the one word, from for to of, and I suspect I knew about KADP when I was at Bedelsford because they would have--, their presence would have been felt around there from time to

time, I think they may have had someone on the board of governors, and the school would have had some relationship with them, but I wouldn't have had any direct dealings with them at all, it wouldn't have been until I went to the Crescent. So from the early '80s onward I would have been aware of KADP. We did a project with them actually, a little fundraising project whereby we helped to raise some funds for them by collecting old envelopes, steaming the stamps off of them and selling the stamps in huge sacks, to stamp collectors, and it was a bulk, it was almost an industrial operation. And it did raise a reasonable amount of funds for KADP so we were aware of that little connection. Some of the people at the Crescent would have been members of KADP, so we'll have done both things and been more than happy to have been involved in both things as well.

Q1: So when would you say you became officially, you know...

A: Aware of it?

Q1: Yeah, worked with them in that respect?

A: I suppose the direct work with KADP would have been around the fundraising project and we would have had other things where we would have perhaps directed people towards them, if there was support that they were offering that would have been relevant. I think initially they had a very different kind of role, it wasn't until they started to work more with Kingston Social Services and developed an advocacy role and started to be involved with the development of the direct payments that we would have had an awareness that there were things that they could provide for the people that we were working with, where there would have started to have been a direct overlap. So I'm not really sure at what point they started to take those tasks on, but yeah it would have been around about then.

Q1: What was your role regarding the Independent Living Scheme?

A: I think we would have been aware of people who perhaps could have benefited from the Independent Living Scheme at the earlier stages of it. I think the people that first piloted the opportunity to be part of the Independent Living Scheme probably wouldn't have been people that were making use of the Crescent at the time, but there would have been people at the Crescent who were active members of KADP who would have known a lot about the development of that scheme and would have been very keen to have had the opportunity to have started to be considered for it. And I think we might have even been asked to approach people, some of our clients to talk to them about what the Independent Living Scheme and to see whether it was something that they might be interested in taking on. Yeah, so from its inception I guess, from the earlier stages of that starting to be developed.

Q1: Can you describe what the reaction to the scheme was, from the perspective of those that were involved in it?

A: There was a real mixed reaction I suppose, there will have been those people who would have probably been early adopters, keen to find out what the new opportunities presented, they will have been aware of those people who were championing that kind of model of care and would have wanted something similar for themselves, so they would have been really keen to find out more about it, find out how it worked, look into what the implications were for them. There would have been other people who were absolutely completely against that idea, and felt that life was quite difficult enough without becoming an employer as well as somebody who had struggles to look after themselves and meet their own needs, and I think that was a quite a big deterrent to a lot of people at the Crescent was that they probably knew enough from their working lives to know that managing people, employing people, managing budgets is quite a taxing experience, and unless there's someone there to help you with it, if you are finding life more difficult than you used to, you would have to be quite naïve to volunteer to take that on if there was no obvious benefit in it for you. So I think for those people their argument would have been if the way that the care is provided to me meets my needs, and all I'm going to be doing is taking away the executive

function from social services, what's the benefit for me, other than the stress of becoming a manager, an employer, and having to deal with things like National Insurance contributions, potential insurance claims, industrial tribunals if I sack someone who takes me to court, you know, and these were bright people, they knew what they were talking about, they would have worked in sectors where they would have employed lots of people, so they weren't naively going along thinking, yeah, that's great, I want to be my own boss, and not thinking for a moment that could be actually an extraordinarily difficult and stressful thing to do. So I think that it was a quite well evaluated reservation, it wasn't one of just fear of the unknown. I think as more people started to take it on, and more people started to find that it worked for them, there were more models around, role models around in the Crescent who could explain, well you know, it's not all roses, but you do get a degree more choice and flexibility, you have more choice over who you employ, and I think that started to sell itself when people could see that. But even now, I think that those people were right to question whether it was as simple and straightforward as perhaps it was being suggested it would be, yeah.

Q1: So what is your current role now in your current job?

A: I work for Your Healthcare and I'm a day centre manager in a resource centre for people with dementia, so it's part of a bigger centre, we have a residential home, and a day centre all as part of the same resource centre, so some of our folks will come to us in the day centre who may ultimately end up living with us in the residential home, I have some overlap, this week I've got responsibility for the home as well as the day centre because my colleague is away, so I act up for her in her absence. Yeah, so that's my job.

Q2: Sorry, I was going to say, so going back to your time at the Crescent, can you sort of just explain how your role evolved I suppose up until the point in which--, did you leave at the point at which the centre closed?

A: Yeah.

Q2: Yeah.

A: Yeah, that the... I suppose there was always a degree of awareness that the way that the service worked was over time, less in keeping with the current way of looking at providing support for people with disabilities. I guess the big change there was that clearly a lot of resource was tied up in the Crescent, and the idea that it was a building based service was increasingly out of keeping with modern ways of working, there was, I think the local authority were looking to try and do more with people on an individual basis and a person-centred way, looking to move more towards independent living and so from within the service we started to run an outreach service, the idea was to try and support people who'd been used to using the Crescent for a long time, to become more engaged in community based support and to make use of more mainstream services and activities. So we wound down our activities and our education programme and we put more of our resource and time into trying to encourage people and support people to go to adult education classes, to go to leisure and activities classes to look at employment opportunities. With the stated intention of reducing their dependence on the building based service at the Crescent. And that was very much inspired by what we saw people were looking for and also what our employers wanted us to do, it may be moved us slightly closer to KCILs view of what was needed and what was the appropriate way of working. But I think we were always conscious that there was a very strong lobby within the disability movement that was very much of the view that building space services like the Crescent were, had had their day and that their time had come to move those resources into a more individualised model of care. That, much like the debate around the name, did fire people up quite strongly and there were times when there were articles in disability newsletters, that singled the Crescent out as being a bad model of care, which the people who used it reacted very angrily to for a number of reasons really. I think firstly because they disputed the suggestion, and also they again felt that it really wasn't for anyone else to tell them how to live their lives, that at the same time as the disability movement was

campaigning very strongly for choices and rights, those people were saying, well my choice is to use a service like this, and it's my right to decide what suits me best, and what you're campaigning for isn't necessarily what I want. And I think that that was a legitimate point, I think that there were people who were very stuck in building based services, who'd been there for a long time, and didn't know how to do anything differently because they'd never been afforded the opportunity. But I think there were people then, as now, who looked back on that time and say that that provided them with a source of support that doesn't exist anymore, and that provided them with not just obvious social outlet and company, but a form of support that alleviated their isolation and often many of the experiences of low mood that were a consequence of the circumstances they found themselves in.

Q2: So what was your job title by the time the centre finished?

A: I was the manager there at that time, yeah.

Q2: Yeah, how long were you the manager for?

A: Ooh, probably about 20 years I think.

Q2: Oh right, okay.

A: I think, yeah, a long time, that's a bit of a rough guess actually, I was a deputy manager for a while, and then manager, I think most of the time when I was deputy manager that the manager at the time was off on long-term sick so I was acting up, so it was a fairly blurred boundary between when I stopped being the deputy and started being the manager.

Q2: You mentioned, sorry, that there were various sort of campaigns that were sort of directed at you and your colleagues in terms of sort of name changes and the provision that you're providing, but were you ever at the receiving end or in support of I suppose other campaigns that were happening locally regarding disability rights?

A: Yeah, we would have always encouraged people to have participated and joined KCIL, we would have promoted their AGM, we took people to the AGM, we provided transport to get people there and encouraged both KCIL members and people who weren't members to go. We would have promoted very hard the advent of independent living, the young disabled people's homecare team, which may have come across your radar already was based in the same building as us. And so that changed model of care was a transition really for a lot of people, from very much a passive recipient of a home carer coming in at a certain time and going when they'd finished, to starting to have a more flexible package of care that would have then led to them starting to take on their own personal budgets and employing staff. And we would have been providing people with training and courses to learn how to be an employer, to learn assertiveness skills, to manage some of those issues around how to manage staff, how to employ staff, teaching people how to do interview and selection, involved them in the interviews that we did for staff at the Crescent, so as they could practice those skills with us and apply those skills when they were employing their own staff. We would have had a management board from quite early on which members of the service were involved in and either myself or the previous manager would have reported too on a monthly basis, looking at the activities we were organising, the staff we were recruiting, the opportunities that we were providing to people within the service to work towards more independence and more independent living. So there would have been a lot of parallels to what we were doing. I think we were always somewhat, I'd want to say handicapped actually, simply because it's in my head at the moment to use that word, we were probably quite handicapped by the way that we were viewed as a service, that some of the more innovative things that we did and attempted to do maybe didn't get the purchase that it would have been nice for them to have had, because in a way it would have been nicer and probably easier for our funders if we'd have just stayed stuck in the past and they would have been able to quietly retire us, well not me, retirement wasn't an option, but they could have wound the service down more easily if we hadn't

had moved with the times. And although we probably didn't move with the times far enough and fast enough for some people's view, it was quite a monumental change for us within the organisation to do that with an enormous amount of resistance from a lot of the people within it. Some staff, generally the staff were more forward thinking than a lot of the service users, some service users were incredibly ambitious for what we could do and what we wanted to achieve, but quite a large cohort were very much more focused on if it isn't broke, you know, it does not need you to modernise it, fix it in any way or tamper with it, we like how it is and we'd like it to stay that was was, you know, something that we had to work against a lot of the time. So yeah, we would have promoted things like there was a campaign of images of a movement, which a friend of mine made me aware of which were really powerful images around the disability movement, and we had large posters of that all around the centre, we would have encouraged people to go on marches, I was aware at the time because of people I knew outside of the work I did, who were very much more involved in direct action, in terms of disability rights campaigning. And some of the people at the Crescent became interested in that, but only a tiny minority felt that that was something that they wanted to or something they were interested in. And I don't really feel that it would have been encouraged at the time for me to facilitate people's involvement in that, although letting them know what was going on where and when, was certainly something that I was more than happy to do, we wouldn't have been taking minibuses to direct action process and blocking roads and Westminster and chaining ourselves to, you know, tube station gates, and certainly not with an obvious social services minibus anyway [all laugh].

Q2: Was there much sort of--, I suppose protests at the time that the centre, that it was announced that the centre was going to close?

A: It was a quite long drawn out process actually, initially the plan was to try and redevelop the centre, because the facilities were very dated, it was taking up a very large piece of land, which could easily have been changed to a multipurpose use which would have been nice, it would have been a more open and less kind of exclusive service for particular groups of people. And there were three, at least three attempts to try and redevelop the service, with a multipurpose health centre and a new community centre, of which we would have had some of the space to continue operating. And I think the later plans all involved housing, rather than anything that was for more community benefit, but for various different reasons none of those plans came to fruition, and I don't think the demands of the Crescent and the Causeway which was the kind of sibling centre for people with learning disabilities that was part of the same complex, I don't think it was our requirements that derailed those projects, I think it was more to do with the profitability of those projects, and what the timescales were for getting them built, what they needed to do to accommodate us, and how much space we needed and could it be done. And so the demise if you like of the services may well have come about even if those buildings had been modernised, they might just have closed the new service in a new building and changes its purpose to something else, it was clear that whatever they did build would not be built in such a way that it could only ever be used as a day centre for people with physical disabilities and learning disabilities. It would have been a multipurpose changeable building, but it felt as though we missed our opportunity to manage to modernise the facility at the same time as modernise the way that we worked. And there were serious problems with the building that would have been extremely expensive to put right, so in a way time ran out for us in trying to get that done. At the same time as there were huge pressures on budgets within social services, and of course there was a very strong sense that if there was to be a squeeze on resources, then it wouldn't be appropriate to preserve the Crescent and the Causeway where a large amount of the money actually went to paying for the building. And that money could theoretically be used to improve and provide support for the lives of people with disabilities through individual budgets and personal budgets. My strong suspicion is that that never happened, that those things, those services were closed and wound up and the money was never moved into a big pot of cash to pay for individual support for people, I think it just disappearing a long with a lot of other cuts that were made at the time, and continue to be made [laughs].

Q2: How did your service users react when the centre finally closed?

A: They were really angry, and some of them still are, they were really angry that the attempts to try and re-provide the service were always bedevilled with incredibly complex planning issues, and multipurpose buildings where private developers clearly had to make money out of the project or it wasn't going to happen. And every time the profits started to look like they were getting a bit more--, the profit margin was becoming a little more troubling for the developers, the first thing to go was the service for people with disabilities, or the size of it was reduced, or massively reduced, or it was more multipurpose or more flexible. And of course, they were fighting to maintain what they had, and maybe in so doing undermined the possibility of anything happening. I don't think it's as clear cut as that, I think the changes of those things coming to fruition were slim, that piece of land is still derelict and it's now six years after the building closed, so if it had been an easy proposition to do something on that land it would have been done instantly, so clearly it's not easy, and it's still going on, as we speak. And so but they were very angry, and they were very frightened, they were very worried about what happens next, and many of those people were offered the opportunity to continue using a day service, one of the existing day services in Kingston that was for older people, and a small-ish cohort of people continued to use that and still use some services within Staywell which is a voluntary sector provider. Because of course the centre they moved to closed down after a couple of years after moving to that as well, so it was kind of there was a degree of inevitability about that, I think that people knew that building based services had had their day and there was not going to be a long-term future for that kind of model. Some people declined to move on to any other service, some people said, "This is it for me, if I can't have this then I'll stay at home and I won't go anywhere," and in a way I suppose they did by default end up with individual packages of care supporting them at home. Some of those people do speak to me when I see them from time to time and say that they don't feel that they are supported in the way that they would like or that they used to enjoy being supported, they don't see people as much, they don't have the diversity of opportunities and activities that were offered when we had that service, but those resources aren't available so it's not just a case of comparing like with like, they didn't close it and then put the money somewhere else, they didn't get that money, they haven't got that much money anymore.

Q2: Frustrating.

A: Yeah, it is frustrating. And I think in a way, from my perspective, that that appears to be the case around the whole of the history of independent living, that if it could have been delivered with the resources that existed 25 years ago, then it would be an extremely different model of service delivery to the one that now exists, and I don't think anybody that was fighting for an independent living model at the time, did so thinking this is going to be unrecognisable in even four or five years' time, let alone ten or 15 years' time. The resources that are available to local authorities and the way that they choose to spend those resources mean that they were never able to deliver that model of care, I came across the advert for the manager's job for the younger disabled homecare team, and when I was looking through some paperwork recently, and it was for the time, it was an incredibly enlightened proposition that perhaps younger people with disabilities might prefer a different model of care to 85 year olds living at home who only want someone to come in and see them to make their tea for them and help them go to bed. And the younger disabled homecare team was a transitional team, it didn't last forever and it wasn't designed to. But I don't think it would exist now, even as a transition, people were unable to participate in leisure activities, educational activities, recreational activities, they had PAs that were employed to support them to go on holidays, it was a world that is very different from the one that we currently live in in terms of what people's assessed need is, and I think I might have mentioned to you when I wrote down stuff that kind of comes back to haunt me, looking back on how things have changed, that a project that I did as, you know, a trainee manager, asked us to look at kind of how the model of disability was changing, and this would have been in the early 1990s and I tried to explain to people the way that Professor Michael Oliver proposed that disability is fundamentally an economic structure, and that you can describe someone as having a disability in a very wealthy western economy, because you can afford to describe them as such and you can resource meeting their needs in a particular way. But if you don't have those resources and you live in a very different economic model, those people wouldn't even be thought of as having a disability, they would simply not either be able to work, or they would be working doing an extremely

menial job that would just about afford them a hand to mouth existence. But they wouldn't be described as disabled because that kind of construct was one of an economic definition. And people looked at me completely blankly when I was trying to explain that and I thought, maybe I've explained it wrong, maybe I didn't understand it correctly, I'm still not entirely sure I understood it entirely correctly. But I think that the way that the world has changed, and the way that the world has changed for people with disabilities, that was a terrifying pre-ascent observation on his part, looking towards the future where there are people that I come across now who are really struggling, but they will not get an assessment from the local authority because they are not deemed to meet their criteria. And as such they're not assessed as having a disability because they aren't in need of an assessment. So that there is a very clear way that that's actually come to pass, certainly locally and nationally too.

Q1: How do you feel what you learned during your time at the centre, how do you think it has impacted on your work experience now?

A: That's, well that's really interesting because I've worked in a couple of related fields, I've worked in learning disabilities, I've worked with people with learning disabilities and I'm currently a trustee of the Kingston MENCAP, and I was very conscious when we were going through lots of changes at the Crescent, particularly with having people like Jane Campbell and Anne McFarlane and Jane Lawrence in Kingston, that it was a real kind of cutting edge model of the change of the way that things were done in local authorities and around disability and disability rights generally. And learning disabilities at that time was completely unaffected by that, it was oblivious to it, it was a very different model, they've changed that of all recognition and they've in many regards they've caught up and possibly they're doing things that are in a way more forward thinking. Working in dementia, it's really only just beginning to start to understand that people with dementia might actually have a view on how their needs would best be met, and might actually have a relevant view on how they would like to be considered, defined, regarded, that's even in some of the services I work in now, that's quite a challenging thought. It feels like that cycle of a few small voices are starting to be heard, a few campaigns are starting to gain a little momentum, but largely in service provider areas that would be a completely alien concept that you would be talking to carers and families and finding out how to meet someone's needs by talking to them. Because of course that supposition would be that those people with a dementia wouldn't be able to tell you how they would like to have their needs met or how they would want to be regarded. So there's a degree of deja-vu [laughs]. I think what's different is that there are not the same powerful voices in Kingston of people with a dementia, saying we're not going to have this anymore, we're not going to be treated like that, this is not the way this should be done. And obviously there is naturally a limitation for people with a dementia, because of the impairment and the way that that might impact on your ability to assert your needs, but there are people who maybe at the early stages of their dementia are much more used to being proactive consumers of services, and they're able to say this doesn't meet my needs, this is nowhere near what I need, this doesn't have any correlation to my life or what I need. And those people at that point are in a position to be able to maybe have an impact on the way services are provided, it is a trickier conundrum, but I suppose you could make the same argument about people with learning disabilities and people with learning disabilities are very well represented locally and nationally in terms of getting their voices heard, it doesn't mean that they can't say what they want [laughs] and can't say how they want their needs to be met in the same way as people with dementia, are just as capable of doing that.

Q1: What would you say is your most proud achievements?

A: Oh goodness me.

Q1: In your work [laughs]?

A: That's a really good question because I think there's a few things that have occurred to me recently that have had the--, the word sustainability used to get kicked around in services probably around ten or 15 years' ago where people started to cotton onto the fact that all services were inherently very vulnerable

and so doing things with a pump primed pot of money that might be fantastically innovative for six months and then have no possibility or prospect of continuing beyond that, were suddenly regarded as being not very good use of money, and incredibly frustrating for people to provide something that raised people's expectations, only to find it wasn't sustainable and it wasn't going to work in the long-term. So there have been a few things that we worked towards when we were at the Crescent, which actually are still going [laughs], and they're still going because they weren't reliant on the Crescent entirely, it was about working in partnership with other people. And we worked with an organisation called Dyscover who are a charity who provide support to people with aphasia, usually post stroke, and we worked quite hard for a short period of time to try and find a way that both the way that we worked in the Crescent and the way that Dyscover worked could work together to meet the needs of some people in Kingston, to provide a Dyscover group in Kingston. And fortunately for us it wasn't too difficult for those two different organisations to quite quickly come to an understanding that actually we both wanted the same thing. And if we worked effectively in partnership there was an opportunity for us to start something that could continue, and the Dyscover Group that we started in the Crescent is still running now, even though the Crescent's gone. So whilst I can't claim responsibility for it I worked on the project that got it off the ground, I worked really hard to keep it going, and I helped to make it happen. Obviously a lot of credit for that needs to go to Dyscover, to making sure it continued, but in a way I suppose that would be my ideal model of making things work now, is that sustainability relies on more than just one organisation or one person's particular vision of how something should be because everybody's pressurised, everybody's got funding issues, everybody has got difficulties and challenges, but you're more likely to make something work for longer if you've got more sign-up from more than just one place. So I think that that is a textbook case of working in partnership between a local authority and a voluntary sector provider, but also the proof of the pudding is that that group still works, it's still running. And there were other things that we tried that were maybe less successful and other things that are still going. There's a brain injury group still runs and we instigated that, and that's a really key source of support for group of people who are largely neglected and overlooked and still are actually, they're a huge unmet need in Kingston and often fall between schools. So to briefly be able to do something about that and still have something that still works afterwards, I suppose is something that gives me a degree of satisfaction. Because as good as many of the things were while we were at the Crescent, the Crescent ain't there anymore and it's not coming back any time soon, so there's always that degree of frustration when you kind of look back on those things, it's nice to meet people who were there, and talk to them and it's nice to hear positive things about their experiences. But it's always tinged with a degree of kind of, I suppose sadness because for those people and for me as well, we weren't able to continue meeting their needs in the way that they wanted.

Q1: I know you've touched on it a bit, but what are your thoughts about the current state of disability support, the support system for disability in Kingston?

A: Hmm. It's an interesting question because it immediately makes me think about the most current cases that I'm working with now, and I don't really--, things tend to get compartmentalised, so dementia is seen as being quite different from disability which is sometimes regarded as quite different from learning disability and that to my mind the challenge is the same, regardless of whatever the particular impairment is that means that someone's needs are different. And I think that the challenge for those people is that there's a very real difficulty in people having their needs met, in a way that actually is appropriate, and up to standard, and safe [laughs]. I have insight into the level of care that people receive at home, when that's been commissioned by the local authority and the homecare providers that provide that care, and whilst there are some good examples, there are a large number of examples of it being absolutely abysmal and a terrible waste of money. It's fundamentally flawed in its thinking, that to try to drive the price down of a service like that you get more value for money, it doesn't take into account that when you push that to its natural conclusion, you are trying to get the most you can for the least amount of money, and if you look at what happens in practice that means a lot of people's needs are unmet, despite the fact that you are actually still spending money on it, whilst maybe spending £15 an hour might look like good value compared to spending £20 an hour, if that £15 an hour is spent on something that is utterly

useless, and at times dangerous, then it's £15 that you might as well have just thrown away, because it's just a terrible negligent use of resources. That's one example [all laugh], there's more.

Q1: So do you want to say?

Q2: No.

Q1: What do you hope to see happening in the future to continue supporting disabled people to live independently, what are your thoughts [laughs]?

A: Yeah, well one of my friends is a very proactive disability rights campaigner and he inspires me, maybe not to be able to work to, in any way, to the same kind of level of amazing dedication and energy that he does, because disability rights have been massively under attack for probably the last ten or 15 years. And it's resulted in things like the Disability Living Fund being closed down, despite a very well-coordinated and organised campaign to try and stop that happening, and what I think I'd like to see is more people being heard and getting their voices heard, so as the effects of those decisions are made clear, the effects of the decisions around funding and how it impacts on individual cases are known about, and that can only help to try and make it more difficult for decision makers to starve the resources from the services and from the individuals that need the support to continue to try and live independent lives. I think there's a false economy around cutting support from people who would otherwise perhaps be able to remain in employment and remain actively part of society, that if you take away their opportunity to have PAs that allow them the chance to get up in time to go to work and to be ready in order to be in employment, then they're simply going to fall back on a source of resources that is completely lacking in any proactive supportive or forward-thinking nature. So you know, tackling those things, continuing to fight on those things and to have the kind of boundless energy to take those kind of disappointments and setbacks and still keep fighting really, that's, you know, seeing more people with disabilities, more disabled people inspired to take that challenge on, must be the key thing really in trying to turn the tide. Because it's not going to happen because anyone's going to suddenly throw more money at it, that I think everyone needs to be realistic and understand that's not going to happen, not without a monumental change of will.

Q1: Jen, I don't know if you have any other thing to add?

Q2: I was just going to ask a question, what was the address of the resource centre, the Crescent?

A: It was in Cox Crescent in New Malden, KT3 4TA [all laugh], it's indelibly etched in my mind probably for the rest of my life.

Q2: And do you remember the date that it officially closed its doors?

A: Wow, I think it must have been, where are we now, 2017, coming up for six years out, so it'll be six years ago this July, so 2011, July 2011 I would say.

Q2: Yeah.

A: Yeah.

Q1: Is there any other thing you'd like to mention which we've not asked, or not talked about?

A: I don't know really, I mean I really hope through the work that you're doing you're able to capture enough of the history of the oral history of the campaign for rights, and that there's a little bit of me that gets very emotional when I think about some of the people who I got to know through working at the Crescent, whose experience of the change that happened over that course of time, was really quite profound, it was a very important time in the history of disabled people, there were a couple that came to

us when it was called the Centre for the Handicapped who absolutely loved the service and were probably its biggest supporters and greatest fans, I think the husband and wife between them came nine out of ten days a week, she had one day off, he came five days a week and she came four days a week, so they did everything that we could possibly offer. And they'd come out of institutional living, and one of the conditions of them coming out of institutional living and this is one of the palatable conditions of them coming out of institutional living was that they would go to a day centre, because there was concern on the part of the doctors that if they didn't they would start to, I don't know, fall by the wayside or do something dreadful would happen to them. And they signed up, so their objective was to get out, that she described it to me as escaping, and that was the way they looked at it, they had to agree to a huge number of incredible impositions and abuses in order to be allowed to leave the institution that they were living in. And coming to the day centre was probably the--, no [laughs], it was definitely one of the least oppressive and abusive expectations on them. And they actually were part of the life of the place, but having gone from being entirely dependent on living in an institution with no real freedom, no human rights, no choices whatsoever, they lived an independent lifestyle, they employed their own carers, they chose to continue using the resource centre, they enjoyed the activities there and they made their friends there, it was where a lot of their life took place, they also were very active in other parts of the community. They were both very strong supporters of KADP or KCIL, both have now sadly passed away, and I kind of want to bang the drum on their behalf, because they're not here to be heard anymore, their voices aren't here. And some of those people's voices and their experiences and the oppression that they were subjected to, has also been lost to history which is tragic really and it's even, I feel even more sad that it's beholden on someone like me [laughs], someone who worked for the council to perhaps be one of the few people that remembers part of their life and what they went through and I'd really like to sort of talk for Tessa and Graham and Alex, about how much their lives were changed. And they were imprisoned because they were disabled, they had no rights, they had no choices, and they had to fight really really hard to get out of those institutions, and one of the conditions that Tessa and Graham had to agree to in order to be allowed to leave, was that they had to agree for Graham to be castrated, as a condition of them being allowed to leave. [Pause]. [All gasp].

Q2: How old were they at that point?

A: They would have been in their mid-30s I think, maybe early to mid-30s, and that Tessa told me after Graham had died, that she had only married him because she knew he would never get out of that institution if she didn't, and as much as she loved him, she had only done that simply to help him escape, and so when you think about the changes that people with disabilities, disabled people have gone through in less than a lifetime, and certainly the Disabled People's Movement were a huge part of bringing those changes about, sadly some of the voices I wish you could hear, you won't be able to.

Q2: Thank you very much, thanks.

[END OF RECORDING – 01:10:31]