ORAL HISTORY RECORDING TRANSCRIPT

'Fighting for our Rights' project

Surname	Ugle
Given name	Sophie
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Q: This is an oral history interview with Sophie Ugle by Jen Kavanagh on Tuesday the 12th of July 2017, the interview is taking place at Kingston Centre for Independent Living as part of their Fighting For Our Rights Project, so thank you very much for being interviewed. Could we start with you stating your full name please.

A: [Coughs] My name is Sophie Ugle, and…

Q: And what is your date of birth?

A: [REMOVED] 1960.

Q: And whereabouts were you born?

A: I was born in West London, in St John's Wood, but I've spent most of my life in South West London, actually here in the borough of Kingston.

Q: What were your parents' names?

A: My mother's name is Virginia, but most people call her Gina, [laughs] my dad's name is Said but most people call him Mo [laughs].

Q: Okay, cool [both laugh], and what are their professions, what were their professions?

A: My father had two long term jobs, one was as a shipping clerk in London and 'cause he's bilingual he was dealing with a lot of shipment of English, British people who were settling in India, and then he was a civil servant for the last 20 years of his working life, 'cause my parents are both elderly and retired now. And my mother has done all sorts of jobs in the sort of domestic field, cooking, cleaning, nannying, but she spent about the last 20 years of her working life as a healthcare assistant in here in the borough of Kingston.

Q: Oh okay, nice connection [both laugh]. And whereabouts did you go to school?

A: I went to school here at Christchurch, New Malden and I went to Coombe Girls' in New Malden.

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

A: I finished school when I was 16 in that boiling hot summer of 1976, which a lot of people remember, and but I did start a day, a part time course when I was between the age of 16 and 18, and I was working at Dickins & Jones in Richmond. And I was doing what they called a buying course, but I wasn't really interested in retail, and then at 18 I entered nursing.

Q: Okay, so can you talk me through your career from when you started nursing to when you then had your daughter, Sophie and so what those years were?

A: Right, okay. So I was at St Helier, Carshalton, where I was a student nurse, and in those days it wasn't degree nursing, it was the old SRN, State Registered Nurse, a three year course, I completed that, lived in the nurses home as nearly all of us did then. Once I qualified I stayed at St Helier's, I was on the orthopaedic unit for a couple of years as a staff nurse, and then I was about--, another two years on a general surgical unit. Then I entered my midwifery, two of my friends were doing the midwifery course and I thought I'd do that, and I fell pregnant with my first baby [laughs], Sarah, who, that was in 1986. And then in quick succession had my three children very close together, so had three children in four and a half years which I had one, you know, at a point I had three children under the age of five. So yeah, so Sarah was the first, and then Kirk was born in 1989, that my son in the middle, and Rachel who's my youngest, and who has a profound learning disability was born in 1990.

Q: Sorry, I have Sophie written down there instead of Rachel, apologies [both laugh]. So she was born in 1990?

A: Yes, yes.

Q: And so whereabouts was she born?

A: She was actually born at home, it was a planned home delivery and she was born at 55 Washington Road, Barnes, SW13, because at that point we were renting a house there, but when Rachel was three we moved back into the borough of Kingston, so there'd been a period of time where as a younger woman I'd been living in other London boroughs, you know, London borough of Sutton where St Helier Hospital is based, and Merton for a short while and then the borough of Richmond, but came back here. And actually came back and settled in New Malden and that was 1993, and I've stayed here ever since. Yeah.

Q: And what age was Rachel when she was diagnosed with her disability?

A: Ah, okay, she was--, it was normal healthy delivery, she weighed exactly the same as her big sister, she was seven pound two, and she wasn't diagnosed at birth, so Rachel was about six, seven weeks old when I began to notice that I thought that there was something not quite right, and finally she got a diagnosis when she was nine months old. At that point the diagnosis was wrong [laughs], the consultant paediatrician, this was at Queen Mary's Roehampton when they still had a children's paediatric department and they still had the maternity department there, that's closed since. The consultant paediatrician thought that Rachel had cerebral palsy, but the physiotherapist who saw Rachel very quickly dismissed that. So then she underwent a whole series of tests, but nothing was formally diagnosed, ironically, even though as time has gone on it's very clear that Rachel's got significant delay, you know, she's 26 years old now, she doesn't speak at all, she doesn't do any Makaton or sign language, or use PECS, a Picture Exchange Communication System. She still wear incontinent pads, she didn't walk until she was six and a half so she is globally developmentally delayed, but significantly delayed. She needs all personal care, but to look at her, you know, with photos and things, some of the time you really wouldn't realise, you know, how disabled she is if that makes sense? They did look at Andermann's Syndrome for a while, a geneticist called Professor [Patten? 00:08:18] at St George's in Tooting thought that she might have Andermann's, and then we had a consultation at Great Ormond Street Hospital, but the professor who was particularly familiar with Andermann's dismissed that, and they couldn't find the deletion of chromosome 15 which is one of the ways that they diagnose it. So yeah, so at the beginning it was all very vague, so she was--, looked like a perfectly beautiful healthy baby, but wasn't meeting milestones, so yeah, Rachel wasn't sitting up, she wasn't crawling, she wasn't mouthing, putting her fingers in her mouth as babies do. She, yeah, wasn't rolling over from her tummy to her back, or her back to her tummy, or trying to pull herself up, so she wasn't making noises or repeating noises back as babies start to do with the first verbalisations if you like, you know, vocalisations, where they're trying to mimic speech, it was very difficult to wean her from milk to solid food. And she was very, very quiet, she was a very quiet baby, and not very curious at the world around her. So yeah, at first I thought it might be a hearing problem, but it turned out to be much more significant that that, and ironically her hearing and her sight are two things that are very very good [laughs] so she can hear perfectly well and she can see, we know that her sight is good from her behaviours and picking things up, etc.

Q: So because she hasn't sort of had a formal diagnosis, I assume that they don't know what the cause of it was, do they?

A: No, no, they don't, no, no. But that…

Q: No, that must be frustrating?

A: Yeah, but there are actually a large number of children and adults like that, and people often aren't aware, they think everybody's sort of got a label, you know, they're autistic, they've got Down's Syndrome, they've got cerebral palsy, the reality is that that's actually not true and it was only through meeting other parents that I realised how many children didn't have a diagnosis, but it was clear that they had significant disabilities, and that some people find that a bit hard to understand. But that is the--, what it is, you know? So the--, you can describe, you know, their behaviours and the delay and their signs and symptoms if you like, but it doesn't come under the umbrella of a diagnosis. Yeah, 'cause you can't find the cause, yeah, no.

Q: Yeah, so at what point did you start sort of identifying that you were going to need supports with looking after Rachel and what services did you access at that point?

A: Oh, at the beginning very little, nothing. We just got on with it, and I did go initially when Rachel was under three years old and we still living in the borough of Richmond, to something called a Hobby Horse Opportunity Group, there used to be quite a lot of them around, and Hobby Horse, they were--, my understanding anyway from, you know, remembering Hobby Horse in Twickenham which was for the borough of Richmond, was that they are like mother and toddler groups, parent and toddler groups, but for people who've got children with disabilities. And so it was held once a week in term time from what I remember, in Twickenham, and then sometimes they'd have a speech and language therapist attend, or community physiotherapist, or occupational therapist would pop in, and say hello to us, and maybe go around and give a bit of advice. But most of the time it was a mother of a Down's Syndrome young man and her son was a teenager, he was significantly older than our children, who had set the group up and was running it.

Q: Okay.

A: So that was my sort of first contact with support, I think really. And it was wonderful, it was really really good, because it was just so good to be with other mothers basically in the same boat, yes.

Q:	And what--, could you tell me Sophie a little bit about Rachel's schooling and where she attended and at what age she first went, which I know was [laughs] not a happy experience [both laugh].

A:	So special educational needs, and the departments in the local authority, very interesting, the whole road to that, oh, and actually I did forget to say one thing, we were--, she did receive portage, under the age of four and a half, before she started school, and portage is a service delivered by children's--, disabled children's services and most of the London boroughs have them, and the portage worker is trained in working with the mother or the parent, the carer, usually it's the mother, in how to support their child with disabilities developing. So it's a whole range of activities that they do, regarding physiotherapy and speech and language therapy and occupational therapy, so it's helping the mother understand, you know, about the use of toys and play, and how they can maximise what--, how to stimulate their child. And so we did receive that service, so that was the first service from the children with disabilities team, that was in the borough of Richmond, and Rachel also did see a physiotherapist, and an occupational therapist actually before she started school. So schooling--, so we moved from the borough of Richmond into the borough of Kingston and by this point I think Rachel was about three and a half at this point, and one of the things I did was I contacted the local education department so I've become aware at this point of the Statement of Educational Needs as it was called then, it's now called an EHC plan, Education Healthcare Plan, but anyway the Statement of Educational Needs, which describes the child's needs and decides where the child should go to school. And I spoke to the head of the SEN department completely by accident I made this phone call, I didn't realise she was the head but she was, it was a woman called Julie, who's left. And said, "Oh, we've just moved in borough, my daughter's got significant delay," I laid it out, you know, very plainly, and said, "Oh, we'd like to start the process, like to start the process to get her statemented," and she said to me, "You don't tell us that your child needs a Statement of Educational Needs," I'll never forget this [laughs], "we tell you if she requires one." And I said, "I'm not being funny, but, I was in a good mood and quite happy and chirpy and made this phone call just in good faith to say that we're here in the borough, my daughter is three and a half, she has no speech, she's in nappies, and she can't walk, please don't talk to me like that," that's what I said to her. I said, "Because what mother would be phoning up to demand a statement when their child hasn't got a disability, all I'm doing is letting you know that we're now in this borough, and that statementing will happen, I can assure you," [both laugh] so and of course it did happen. But Rachel went to Corpus Christi, which is a little Catholic school in New Malden for the nursery bit, which worked very well, so she was integrated into mainstream nursery. As time was moving on and that year that she spent in the integrated nursery I did realise that, you know, the delay was really significant, and that actually for Rachel's needs a special school was important, was the right thing to do. It's not for all children with disabilities, and I believe in integration fully, but my daughter has profound learning disabilities. If she had had physical disabilities or sensory issues, sight or hearing loss or something I would have fought hard to have her integrated in mainstream. We went through the statementing process, and we went to visit Dysart Special Needs School which at that point was in Ham, in the borough of Richmond--, no, in the--, sorry, in the borough of Kingston, but it was very close to the borough of Richmond, so Dysart was the severe learning disabilities school, and Rachel started there at the age of four and a half. And the home transport would come and collect her in the morning and drop her off after school, and her older brother and sister went to the local primary school, Burlington, which was on our doorstep 'cause we live at--, literally at the back of Burlington School. So the experience of her going on the bus I found difficult, because she was so young [gets upset].

Q:	I'm sorry.

A:	No, that's alright, yes, so yeah, that was difficult, you forget the things that were difficult. Just it's weird talking about it really. You--, yeah, you do forget some of the things that were difficult. So in Dysart, I've got the highest regard for Dysart, it moved when she was seven years old, the location of the school, and it's now along the Ewell Road in Surbiton and it's still the borough of Kingston's school for children with severe learning disabilities. The age range is huge, it goes from nursery basically to the age of 19.

Q: Oh okay, yeah. Yeah, it's been mentioned by a few people, but yeah, but not anybody that actually attended there, but just in sort of a general sort of discussion about the provision in the borough, but it's, yeah, but you found the experience positive for her?

A: Oh yeah, I found the community and the teaching and the support really good, I mean on site they've got, on both of the sites that they were at they've got hydrotherapy pool, they've got physiotherapists based at the school, occupational therapists, speech and language therapists who were always highly amusing, 'cause even when they talked to the mothers they would be doing Makaton, I'll never forget Jane Chapman doing that, and I'd be saying, "But Rachel's not here," she said, "Oh sorry," [laughs] she used to just do it naturally, and Sue Strudwick, they were hilarious. Because it's a very small school the--, and I mean I think when Rachel went there were only about 70 pupils there from throughout the whole school, I think it's my understanding now there's about 120, so you know, this is a--, with severe learning disabilities you haven't got huge amounts of children, it's in more--, the world of moderate learning disability that you see higher numbers, and so hence St Philip's in Chessington which is the MLDs school, has got far more children than Dysart. So because Dysart is so small, the parents that were really involved in the school you got to know really well, so we did miss the meeting at the school gate, that's always difficult, because traditionally that's where a lot of mothers meet other mothers, it's when you're dropping off your children and when you're collecting them, but when you've got a child at a special school on the--, [coughs] on the whole you're not dropping them off or collecting them, because it's a centrally located school that everyone across the borough is going to and therefore they have school transport. So there are things that you really miss out on, but we developed links and got to know one another, the parents I mean, through meetings at the school, through the Christmas fair, the summer fair, being part of the parents group, FODS, Friends of Dysart, helping organise the fairs, you know, and the school fairs, so you got to know people like that. And those relationships were very very strong, and with that group of mothers. But then it all disappears again when your child leaves school, and all of them go into transition and they enter the world of adulthood, so it's hard, you go through all these different phases and experiences. And some of the time it can be very isolating.

Q: Yeah, I can imagine. I wanted to talk to you about the, well the various sort of activities that you've been involved with and action that you've taken over the years, but what were the sort of initial challenges that you faced with Rachel and particularly sort of the provision that was available, to sort of inspired you to want to start taking action within the borough?

A: Well I'd never even really thought about it in any great detail, but as I said, you know, my background's nursing, so I was a qualified nurse with three children and a partner, and you know, me and their father were living together then. And I'd always considered returning to work, but when I started enquiring about childcare and the reality of getting childcare for a child with a disability, I began to hear sort of, yeah, brick walls, everywhere, and realised that there is huge obstacles, and huge inequality, so on the one hand the government in this sort of period of time were thinking a lot about childcare and there was a big campaign called Thinking Big: Childcare for All, which was launched I think by the Labour government, I think it was Blair's government, it was during that period. And it was called the National Childcare Strategy, and that they were rolling out, and the slogan was Thinking Big: Childcare for All, and I wanted to return to nursing, part time, and to help with the finances of the home, obviously, and I couldn't find childcare for Rachel. And then I was aware of this National Childcare Strategy that the government had launched, and within the documents it had targets, and it said quite clearly that its targets were aimed at single parent households, ethnic minorities, childcare for disabled children, and keyworkers. At that point I wasn't a single parent, me and Neil were still together, but I was a keyworker and I had a disabled child [laughs] and I happened to be a mixed race woman so I fell into the sort of BME category as well. And so it was quite naively in a lot of ways because I'm the sort of person that when I read literature, not literature, but factual evidence and documents I just assume it's going to be carried through, so this opened a whole new world to me of policies and strategies that I was completely unaware of. And I thought, well if you had this book, you had this booklet in your hand and it says this, this and this, then the local authority would just give it to you, and that's what I did, I went to the local authority, and I said, "Well but in this document it says Thinking Big: Childcare for All and specifically it's talking about disabled children, and children from BME communities, which Rachel is both of those, and looking at key sector workers, so can I have some childcare please, I'm happy to pay for it, but I'm having difficulty getting childminders or people to come into the house to look after Rachel because of her needs, they're saying, oh no, we can't do that," I said, "I've gone and knocked on the doors of holiday clubs and afterschool clubs." And a particular one was at the Malden Centre, which is in Blagdon Road, where I still live, and they've got lovely holiday clubs and afterschool clubs there, and I said, "Well can you take my daughter?" and they said, "No, not unless she has--," well first of all they said no outright, they actually said, "We don't take disabled children," you've got to remember this is the 1990s, so then I looked at their policy and it said, talked about equal opportunities and non-discriminatory practice, and had in their disability, you know, we do not discriminate against children with disabilities, ethnic minorities, blah blah blah. And so I went back to their manager and said, "But you've just told me that my daughter can't enrol in afterschool clubs and holiday clubs, because she's disabled, but this is what it says in your equal opportunities thing." So there was lots of discussions between the local authority, the Malden Centre and me. And I just kept presenting them with their own legislation, and saying, "But this is what you are saying, you're saying that you don't discriminate, but you are, you won't let her in the club," but and then they said, "Well we will let her in the club, but you've got to pay for one-to-one support for her." So they changed their minds, so I said, "Well, how am I going to do that, you know, and if I was going to pay for one-to-one support if I could do that, I would have probably one-to-one support in the family home for her," and I hadn't been able to get that because I couldn't get a childminder to look after Rachel either because I was coming up against the same problems. So it--, this went on and on and on, and I ended up writing a document in April of 2003, called,' Thinking Big: Childcare for All, how the national childcare strategy is failing disabled children and their families in the royal borough of Kingston-Upon-Thames,' and I sent it everywhere, not literally everywhere, but I sent it to a lot of people, I can't remember who I sent it to, I sent it to the Secretary of State for education and skills, to Baroness Ashton, who was then the DFES, Edward Davey the Kingston Surbiton MP, I went it to local councillors who were sitting on the young people and lifelong learning, the chief executive of RBK, the director of education of RBK, social services, and it went on and on and on. Did I ever sent it to KCIL, I don't remember.

Q: Yeah, I was just having a look.

A: Yeah, maybe I didn't at this point, I sent it to the Childminding Association, Kingston Carers Network, and I also sent it to national organisations, Daycare Trust, which I think has changed its name since, MENCAP, and I sent it to an organisation called Working Families, that had a disabilities project, Contact a Family, the chief executive, Francine Bates, Philippa Russell the director for the Council for Disabled Children, Scope and the Down's Syndrome Association, even though, you know, Rachel doesn't have cerebral palsy or doesn't have Down's Syndrome. I just made the decision to send it wide, and I then just became involved in like a one woman campaign really, I'd outlined--, you know, this wasn't some great research project, it was something from the heart really, and I described our own circumstances, I described who I was, and the family makeup, and then at this point I'd become a single parent as well, and described that. And then I described the different childcare arrangements in the borough of Kingston, and my experience of asking people for childcare, and I quoted slogans from the National Childcare Strategy, and how I couldn't find it, I couldn't--, or if there--, that, and I talked about mainstream childcare and specialist childcare. So for instance at that point even if I was prepared to put Rachel in specialist childcare, which I didn't actually want to do and I'll go onto those reasons, the specialist clubs were only open three times a week after school, and then in the summer holidays it was only open for four weeks and it ran from ten o'clock till five o'clock, so if you worked nine till five you couldn't work anyway. But also the four weeks that it ran you couldn't book your child in for four weeks, you were only allowed ten days out of the four weeks and you had to--, it was like some sort of bartering system, who knows, whether they pulled children's names out of a hat or whatever, but this was sort of token childcare in the summer holidays, supposedly to give mothers a bit of respite. Right, because the demanding needs of their disabled child, I used to find that highly patronising and I still do, I don't like that approach to the whole world of children with disabilities. So instead of thinking about the child's needs, the child's experience, and also the family's needs, yeah, granted, because if you're looking for childcare it is, it's also about the parents needs as well. But instead of looking at it in an equal way to able bodied children, we were often given token little bits of afterschool clubs and holiday clubs because of the realisation that it was so terrible struggling with a disabled child. Yeah, so the emphasis was quite different, and very negative really. Because Rachel went to a specialist school, and I was content with that, one of the things that I argued was that childcare was an opportunity for Rachel to integrate with able bodied children, and basically what happened, even though this was written in 2003, in 1999 I secured three afterschool clubs a week for Rachel at the Malden Centre and I paid for the clubs, and the local authority did decide to pay for extra support for her. So when the bus, instead of the bus dropping Rachel off on a Tuesday, Wednesday, Thursday at home, they dropped her off at the Malden Centre which was literally down the road from our house and then when I finished work I simply collected her from the Malden Centre and brought her home. It was the very first disabled child that the Malden Centre had ever had in any of their holiday or afterschool clubs. And it's quite extraordinary, when I think back on it, because she was so, is, you know, is so significantly disabled, and is very sociable, loves other children, I mean Rachel just adores other children, even now she loves children, and she's an adult. And it was very special, her being integrated there, because members of our community that didn't go to school with Rachel were at afterschool club or holiday clubs with her. I remember being in a supermarket in New Malden and a child sort of pulling on their mother's arm and pointing at Rachel and going, and Rachel was in her wheelchair, was going, "Rachel, Rachel, she's in my club, she's in the club," and the mother was going, "Oh don't be silly, she can't be." Never forget that [both laugh], and then and I said, "Actually, she is, she is in the Malden Centre afterschool club," and the mother went, "Oh, oh okay," but it was like she'd wanted to deny that she was. But what was interesting was that this child was delighted to see Rachel in the supermarket and was trying to tell her mother that Rachel went to the same club as her, but there were lots of experiences like that, not so negative with the mother denying it, there were lots of positive experiences where the parents did know that Rachel was at the club and people were coming up and talking to us in the high street, out and about, in the park and children coming up and saying, "Oh I played with Rachel at the Malden Centre." So that was fascinating, that wouldn't have happened if she hadn't have been integrated in those clubs. The other thing that happened with the Malden Centre was because it's got a swimming pool and Dysart's got a hydrotherapy pool, the combination of her being there in holiday clubs at the Malden Centre, and Dysart in term time, meant that she was swimming all year round, she was in the pool, and she is a competent swimmer. So for a young woman that has to wear incontinence pads, that can't feed herself, that didn't learn to walk until she was six and a half, and her mobility is a bit, you know, unstable because of that, it's obviously--, and for some, you know, somebody who can't talk, she can swim, it's amazing, no armbands, no floats [laughs], she can swim, up and down, up and down the pool. And people are always really impressed by that, but it was this combination definitely of the Malden Centre and Dysart. So a lot of good things happened with the Malden Centre, even though the beginning was really negative, and they actually said, "We don't take disabled children."

Q: Yeah [both laugh].

A So [laughs], "We don't take disabled children," I said, "Try saying that to somebody of colour," I said, "would you say we don't take black children?" you know, and I felt very confident in saying that being half Asian, you know, and that that wasn't meant in a derogatory was, but just is this what you would say? You know, you just wouldn't do it. But they felt comfortable in doing that. A lot of people at the time asked me why did I bother pursuing with the Malden Centre, and I said, "I knew that's where I wanted her to go," and I did feel that once things were set up that they would sort of take it onboard, I had a sense of that. And it's in the road that, you know, we live in, and the whole community uses that centre, and her big brother and sister use the Malden Centre all the time, and particularly the swimming pool. So I knew it was the right place.

Q: Yeah, it's important.

A: Yeah.

Q: So from that, how did then the Kingston Special Needs Group get set up?

A: Ah, right, so Edward Davey became the first Lib Dem MP, oh gosh, was that in 1997? I think it was. Anyway, he had received a letter from me about childcare, and he'd also received letters about speech and language therapy, and other issues to do with children with disabilities, from Sue Baker and Liz Mayes-Reid and Julie T Wallace, and we didn't really--, we didn't really know one another, I had met Sue and Liz at that point, but I'd never met Julie, and basically he brought us together. Because he'd got in his mailbag some letters from different mothers about issues that they were having regarding special educational needs, speech and language therapy, whatever, statementing, a variety of issues, he actually introduced us to one another. He invited us all to a meeting to one of his surgeries and I remember they used to be on a Monday morning. We then--, he said, you know, "You've all got different experiences, you're all quite outspoken ladies," [laughs], "is there something you can think of doing together?" and he said, "I would be supportive of that," and that's how Kingston Special Needs Project was born. And so he was very supportive, I don't know if I've got a picture of that? I don't know, I'm--, I did have a picture of all of us together, but yeah.

Q: Okay, so how did--, what were the sort of aims of that group, what were you looking to achieve?

A: We were--, so we were looking to achieve a sort of variety of things, this is--, so we were looking to achieve better speech and language therapy, quicker access to speech and language therapy which never seems to have been achieved, because there were children with significant speech and language issues, who are all nonverbal, completely, two years on the waiting list, under fives, so your maximum, you know, time to be working with children is when they're under five, we all know that, it's not rocket science, you don't need to be a professional to know that, that's the time where children are developing all their skills and if you lose that it's very difficult to catch up, basically, it's very very difficult. So speech and language therapy was a big concern. The whole statementing issue of how children get statemented, and what's covered in that statement because it's a legal document, you know, it's part of the Education Act, and what provision should be given by the local authority, and my campaign was around childcare and play. So those were my sort of two biggest concerns, and the others as I said had, you know, the variety of other issues. Although they--, it's not that they weren't issues for Rachel, but they were sort of covering those bases and I had a sort of different interest if you like. We held meetings, we went to the press, we had social events, often at Warren Park Children's Centre, which I--, see because I've lost a bit of touch with children's services in the borough I don't even know if Warren Park is still there. So Warren Park was run by National Children's Homes, NCH, but they're now called Action for Children, but they ran it on behalf of the borough of Kingston, on behalf of the local authority. It's a big centre on Kingston Hill, newly built with respite care provision, so it's got beds there, and a big play area in the middle and a huge garden that backs onto Richmond Park, and it was used for all sorts of activities, so some holiday clubs, as I said, but they only ran from ten till five and you weren't allowed to have more than a certain quota, etc [laughs]. Afterschool clubs and with the same issue as well, it was very rare that you got more than two afterschool clubs a week, they were rationed, so even if you wanted to work three days a week for instance, because you know, for a lot of part time staff three days a week tends to make more sense than two days a week, you know, financially wise, you know, you often hear of either three days a week or five days a week, well you couldn't get three afterschool clubs at Warren Park [both laugh], you weren't allowed three afterschool clubs a week. So [laughs] it was a nonsense, but loads of activities took place there and Kingston Special Needs Project used to meet there, we used to be able to book the main room and meet there. And it flourished for quite a while, for a number of years, but then between us all the mothers--, the mums went their separate ways and would--, we were doing other things. I carried on with the campaign for childcare, and continued and was invited to do loads of work, which I've sort of got in front of me, so I was invited to a--, to sit on the steering group of a piece of research called On Holiday, with the Thomas Coram Research Unit, which is quite famous, the Institute of Education, and you can see there that--, there.

Q: Okay, yeah.

A: So I was sitting with--, these were really interesting characters, so Philippa Russell was the director of the Council for Disabled Children, and Christine Lenehan was working in head office, in Golden Lane for MENCAP regarding--, oh no, sorry Lesley Campbell was, Lesley Campbell was a head office of MENCAP, for children. Christine Lenehan, my gosh, trying to think what she did, so we all came from--, well Utin Nevadi I think worked for an organisation about play for children, and we were--, I was part of the advisory panel for this piece of research, and the steering group and it looked at two London boroughs I think it was, and two authorities outside of--, no, it was more, so it's got--, what it was, it's such a long time ago I forget everything that I've done [both laugh]. And basically it was saying that the children, the young people and their parents were experiencing a lack of childcare, you know, and a lack of activities, and a lack of play, and a lack of integration. You know, these were the messages, big messages that were coming out. And that the children were extremely isolated, in particular in remote areas it was really difficult for children to join in activities, disabled children obviously I'm talking about. And it was about provision, you know, what provision is needed and how can we move on from all of this, what can we do to help. I've always thought quite strongly that play and childcare is a fantastic opportunity for disabled children to integrate. Where you've got children at special school why can't the children come together in play, it's not going to affect anybody's education, you know, this should be happening. But we still are in a position where you see specialist provision and mainstream provision, even with childcare. Which I think is really sad.

Q: Yeah.

A: But yeah, I mean it's they're just missed opportunities all the time. We--, a conference was called in Kingston called Breaking Down the Barriers: Inclusion for Disabled Children, that's a picture, that's Rachel there. And I was invited to speak so I was one of the speakers involved in that, and oh sorry.

Q: That's alright [laughs].

A: And Philippa Russell attended from the Council for Disabled Children, Bruce McDonald the chief executive of Kingston, I mean this was a major conference, and it was really well attended, but the thing I'm seeing is that, and we, you know, we even had Jayson who's got--, who's a young man with a disability, and still lives in the borough, speaking at the conference. But I've not seen anything like this for a long long time in the borough.

Q: What year was that?

A: Do you know, I wonder if this is--, this was years ago, I--, do you know it hasn't got a date on it, I think this was about 2003.

Q: Okay. And that was the time around the time that you had written your reports?

A: Yes, yes.

Q: Yeah. So you had formed the group with Ed Davey as sort of…

A: Yes, yeah.

Q: To collate it before you wrote the report, is that right?

A: Yes, yeah, that is, yes.

Q: And that came out of your campaigning?

A: Yes, yeah.

Q: What response did you get to the reports?

A: Ah, right, so then I realised that you see what you've got to do, it's no good just writing a report and sending it to people, then you have to chase it up, didn't realise this, you have to chase everybody up you to see respond, and so I was getting into the swing of what I needed to do, and so I started chasing everybody up [both laugh]. There were people that were very good at responding, and others that were not so quick, but I realised that it was important to sort of keep that bit of pressure on, and the responses I was getting on the whole were very positive, people were saying, "Oh of course we believe in childcare for all, we've got the National Childcare Strategy, you know, disabled children are often living in poverty, they're more likely to be with a single parent," the divorce rate, or break-up rate, whatever you want to call it of parents of disabled children is three times the national average, particularly if you have a child with a severe disability. So although I don't like talking about my child and our experiences in a negative way, there are impacts for families, and that is one of them, there's clear evidence about marital breakdown and family breakdown. I mean one woman that was very close to me, I don't really want to mention her name because it's not, you know, I'm not talking about me, but I know that as soon as her husband, and she'd been married for many years and it was their first child, found out that the child had Down's Syndrome, he walked out, basically. He walked out, they'd been married for 12 years prior to having the child. So you know, that's very telling about how people can react, this, you know, it can be, yeah, yeah, very difficult. I don't know why I'm talking about that, why am I talking about that, I suppose I was talking about single parents, yeah.

Q: Did you feel the report and obviously the campaigning you were doing had a positive impact, do you feel that changes were made, did you see changing being made?

A: Yes, so one of the big changes that happened in the borough of Kingston was the development of Yorda Adventures, and although it is specialist childcare, and specialist provision, there is no doubt that because I was bringing this to everybody's attention, we were in the local press, so you can see articles here from the *Surrey Comet*, and we were in the national press, in *The Guardian*, that's Rachel, a lovely picture of her isn't it?

Q: Oh wow, yeah.

A: We were in specialist magazines about childcare, about one parent families, and disability, and you know, the lack of opportunities. And I was saying quite clearly, "You keep telling us that we're more likely to be in poverty but you won't let me work and that also means that my child can't get access to something really positive where she can play with other children and have that positive experience." And actually it was more important for Rachel than her able bodied brother and sister in a lot of ways, because of her significant disabilities, to have something structured with regarding play, and to have that social stimulation, and stimulation from play and activities. It was more important, she couldn't go and run off and climb trees, and sit in the park poking mud with a stick, or whatever, and make her own sort of self-discoveries, she couldn't, you know, she can't--, and she still can't do that, she needs a huge amount of support to be able to access very small things, you know? And so it for me it was became an absolute passion that why were our children being denied something so meaningful? And people did, they did begin to listen, funding was created for support workers to support children with disabilities in mainstream clubs, if they needed that extra support, and funding was created for Yorda Adventures, and Laura Smythe who runs Yorda Adventures has always said that it was because of me [both laugh] and I agree with her [laughs], it was because of me. And so I was talking as I say to specialist, you know, people, I was invited to repeated conferences to talk, I spoke at conferences to do with MENCAP, every--, during the Every Disabled Child Matters campaigning, we contacted Family and MENCAP, I was sitting on steering groups, trying to deliver the message. And it went on and on and on, and I became involved with two particular organisations that were very supporting, the Working Families, Waving not drowning, so that's national. There's another picture of Rachel. And Daycare Trust, and those two organisations both awarded me for my campaigning, so the first one was, oh yes, and we were all over the place, Children Now, so there I was talking about special needs there, and disabled children, so yeah. So the--, sorry, the first award was with Daycare Trust, and I won a special award in 2004 and received that from Gordon Brown along with some other people, I wasn't the only one, that Daycare Trust had put me forward for. And it was for the campaign for Childcare for Disabled Children. And then in--, so then in 2006 Working Families had their 30th anniversary, and they named 30 pioneers, and interestingly enough some of the women in this, that are pioneers and men, there were some men as well, Shirley Conran who's the wife of Terence Conran was there, Harriet Harman MP, Margaret Hodge, Patricia Hewitt MP, Theresa May was [laughs] one of those honoured, who is now our Prime Minister. And little old Sophie Ugle, 'Honoured for her passionate and committed campaigning for the rights of parents of disabled children.' So it was good, so yeah, I have got a picture somewhere of me and Theresa May and Margaret Hodge and, you know, where they took a group photograph, there is a picture somewhere but goodness knows where it is, I don't know where it is now, so it was an interesting time. And I do feel that it was successful campaigning and things did come out of it, but there's no doubt we've regressed.

Q: So once Rachel was a point--, well I suppose at an age in which she well was--, was there a sort of cut off in terms of age in terms of when she could no longer access services at the Malden Centre or has she been able to continue?

A: Right, so yes, well that became very interesting, because for mainstream children, childcare normally ends at about 14, because by the time a child is 14, 15, parents are usually willing to allow them to stay home alone, yeah, or with their brother or sister or whatever. Or maybe have a little bit--, you know, that there may be, you know, going around to grandma's for a bit, an auntie's or something, the care is not so significant, it's more about being mindful as to what they might get up to, especially in the long summer holidays [laughs] if you've got teenagers. So the Malden Centre stopped at 14, so Rachel could no longer use it, but by then Yorda Adventures was set up for specialist care, and I did then put her into specialist childcare. And that went right up until she left school. So they took her from the age of 14, 15, about 15 actually, the Malden Centre did hang onto Rachel until she was about 15, they didn't say at 14, "Oh she's got to go, straightaway," so I think it's while we were trying to set things up from what I recall. Yeah, and then she started using the specialist care, yeah.

Q: And then what age did--, does she continue to access that provision today, or has that--, up until she left school did you say, sorry?

A: Yeah, it's up until she left school, because children's services are one thing, and adult services is another, and as soon as your child becomes an adult, which is actually officially on their 18th birthday, although the Statement of Educational Needs goes up to the age of 19 in the borough of Kingston for those that attend Dysart School. But basically from 18 onwards you're then entering adult services, so then it changes. But then something happened when she was 18 which was devastating and she developed severe uncontrolled epilepsy, completely out of the blue. And that had a whole sort of set of repercussions, I was hoping that Rachel would live with me until she was about 25, but by the time she was 21 and I was struggling to maintain working and looking after Rachel, so and find appropriate care for her, day centres and, you know, as I say you're then looking at adult services, so then when she was 21 she moved into supported living. And she lives in Surbiton, in Ditton Road with four other young adults, from this borough, they're all in their 20s, and in fact one of the young people at Ditton Road who lives with her, the only boy in the house, or young man I should say, he was at the same school as Rachel, they were actually in the same class, they went to Dysart together, so you know, it's that that's been good, but it's also been [laughs] difficult.

Q: I can imagine [both laugh].

A: So we've had to find things for Rachel to do to stimulate her, you know, she's not going to work, and they're all profoundly learning disabled in the house and all of the five of them are nonverbal, and all have very high needs. But what we've done with Rachel is I've organised a sort of timetable with the house, so that her support workers take her to different activities, on a Monday evening she goes to MENCAP Seekers, Kingston MENCAP Seekers, on a Tuesday she has music therapy at the Hook Centre, and that's by a specialist music therapist who works across the boroughs of Richmond and Kingston, specifically with people with learning disabilities. On the Wednesday she's at EnhanceAble Day Centre for the day, which used to be part of Scope years ago, it was called Scope, Geneva Road in Surbiton, but now it's called EnhanceAble and now is a mixture of people who use it, there's not so much people with physical disabilities, it's that some people might well have physical disabilities, but now it's more people with learning disabilities that go there, and she had physiotherapy and art therapy there on a Wednesday. On a Thursday morning she normally goes swimming, and on a Friday afternoon she goes to Danceability, or Zumba, for people with learning disabilities at the Hawker Centre in Kingston. So you know, I've managed to sort of devise a package of care, I've given the house ideas about storytelling, and in fact this morning was the last session of three where the speech and language therapists have developed once a month, or this was on a trial basis, storytelling for people with profound learning disabilities in Surbiton Library, so they delivered it at the library and that is entirely due to me. Because I did a bit of research on it and I looked at what they could do, I've thought really--, I've thought very carefully about where it should be delivered, and who can deliver it, because there's a huge lack of activities for people that are severely disabled, who have got really complex needs, you know? And I thought, sensory, sensory storytelling would be really beneficial, and it's been a big success, so this was the pilot, that's what it's called, pilot scheme, these three sessions. So this morning was the last one, I haven't attended any of them myself, my daughter's attended with support workers, and in fact the whole house has attended. But I'm hoping that the speech and language therapists will continue it, but like all these things they could so easily turn around and say, we haven't got the money, but we will see what happens [both laugh].

Q: Yeah, what are your sort of current thoughts on provision in the borough, obviously funding plays a huge impact on what is available.

A: Oh yes, yeah. And one of the--, I was in favour of the day centres closing, I was one of the people who was very much in favour of, yes, let's do stuff out in the community. But what people need to remember is that if you're toddling around in the community with a support worker, that isn't really being part of the community, and that can be isolating in itself, because people end up just going bowling or to the cinema, or out for a meal just with their support worker. Particularly if you've got high level needs, so they're not really integrated into a club or something that's, you know, a group of people. I made huge efforts on this, because I'm a huge believer in it, of getting Rachel linked into the Surbiton community where she lives and involved her by me taking her to all things to do with Seething Wells, and Seething Wells is a group of people who are basically barking mad, and I'm allowed to say that, and they're full of artists, musicians, dancers, they're very creative, Robin Hutchinson who is a very well-known character in this area, has created this group of people, and they put on little festivals and they've had sports days for instance, at Victoria Park in Surbiton where all the sports were old fashioned sports races, egg and spoon, sack race, you know, all those things you did as a kid. But it was--, they did it for children and for adults, the sports--, the races, and huge beer tend, ice cream van, lots of different, you know, other stuff, face painting going on, and live bands, there's a lot of music involved in what they do, live bands playing and a real sense of fun. 'Cause they're a bit quirky and a bit different and I made sure that I took Rachel, not the support workers to all of this and I absolutely knew what I was doing, but I already knew people within this group, but what I was doing was knitting her in to the fabric of this group, so she was a part of it, and introducing Rachel to people, and get--, encouraging people to talk to her, and getting her out of the wheelchair when the live bands were on and getting her up and dancing which can be a bit hair raising because of her epilepsy because she wears a crash helmet. But she absolutely loves dancing and she just sort of jigs about in her own little way, you know, and it's really sweet. But making sure that I was getting her involved, you know, and talking to people, talking to the local photographer called Tanglefoot, and talking to Simon and talking to Sharon and talking to whoever, and constantly building up these links, then she's got a Facebook page, and now she's friends with loads of these artists and people on Facebook, and so they get to see what she's doing when she's not at Seething Wells, and pictures of what, you know, Rachel's doing. And then last year, on Rachel's behalf we nominated Seething Wells for--, there was an insurance company, was it Aviva, I can't remember, that were looking for organisations that worked with communities, basically, and the first prize for the local groups was £1,000 for a picnic, so Seething Wells won the London region, there were ten finalists, and the national prize was £25,000 for that community group. And we went up to the Barbican and Gabby Logan was presenting the awards, and Rachel got really excited when she saw her face, the picture of herself, representing Seething Wells 'cause she'd nominated them, and Seething Wells won. So they won £25,000 because I nominated them on behalf of Rachel. And which was extraordinary 'cause we really did not think they were going to win out of, you know, all the finalists in the UK, and there were a lot of good groups there as you can imagine, and in fact there were groups there that were working specifically with people with disabilities, but Seething Wells doesn't do that, and actually that's what I like about it. Because they are embraced my daughter wholeheartedly, and encourage us to go to things, and are very warm and welcoming. Now it might not be completely accessible in the terms of how an organisation like KCIL might view it, right? With where some of the activities are, yeah, and how you get a wheelchair around, but what we do is we manage, because I like that quirky off the wall band of musicians singing sort of, you know, folk and indie and what have you, and acoustic guitar out in the middle of a field, you know? Having fun, and they're all people from around here. And it is, it's great, it's absolutely great. And for her to have those experiences also she's got the freedom 'cause they're outdoor events to vocalise, 'cause she does make vocalisations, and she can get very [laughs] elated when there's music, and sometimes like if it's in a theatre or if it's in a building people stare and people look, whereas if it's in open spaces it's a very different feeling. So yes, we're sort of fully integrated into seething wells and she, you know, she's been attending everything that's been going on and they've had loads of their summer events already, but and I think the next thing they'll be putting on is in October.

Q: Okay, well I'll keep an eye out, it sounds amazing [both laugh]. So in terms of sort of overall provision, particularly at the age that she is now, what do you hope to see in the future in terms of the services that are available in Kingston?

A: Right, I now recognise there's a need for the day centres, right, so I have changed my view on that. Although you have to work very very hard like, like I've explained, to do a piece of community work, with someone like Rachel, the effort has to be enormous and the passion to do it. And most support workers ain't going to cut it, they're not going to do it. So the day centre I think, the day centres need reviewing, there's two day centres in the borough of Kingston, HFT, which is in Kingston Road, and EnhanceAble which is Geneva Road in Surbiton. You know, there was a day centre for people specifically with physical disabilities, that's gone, I think that was called the Causeway Centre, it was in New Malden.

Q: Yeah.

A: In fact which is right next door to the Malden Centre, yeah, that's where it was in Cocks Crescent, there. And EnhanceAble initially was as I say Scope, and originally was for people with physical disabilities. That whole world has changed and, you know, a lot of people with physical disabilities do not want to be going to a day centre, so now we need to really scrutinise what's happening for people with learning disabilities, some of them can engage in community activities, and I know that they're doing that, some young people through Kingston College, through gardening schemes, through work experience, in shops, in childcare, in supermarkets, what have you. So the day centres have to really think carefully about people with severe and profound learning disabilities, because that's where the gap is. They're being left out, and there is not enough provision for them. And people don't know what to do with them, because you can't sit my daughter down and go, "Oh, paint a pretty picture," or, sit on the computer and do a computer game, or, "Let's go out and choose shopping and cook a meal," yes you can try and put those things in place, but the reality is they need far more specialist intensive sensory stimulating activities, from really skilled practitioners, so things like intensive interaction, and sensory stories. And I'm not seeing those practitioners here, they're not visible to me, and you know, I had to, as I say email, beg, put together a whole proposal for having a pilot scheme for three sensory stories, you know, in May, June and July of this year. And we'll see what comes of it, but you know, did anybody else ask, you know, did any--, did, you know, people are--, the thing is, lots of parents are asking for things, but they often don't go with a proposal and that's what I've learnt to do as well, instead of saying, "Oh, we want more stuff for people with PMLD," and then you go, and say, "Oh what do you want?" "Well we want more stuff," and then writing it on a form, and then you go, nobody does anything, "Oh we'll just tick the box, 'cause we want more stuff for people with PMLD," it doesn't get you anywhere, nobody listens, nobody takes any notice, which is not fair really, it's not fair. It's far better though, it works better if you can go with a solid proposal, "This is what I'd like to see happen, can you put it in place." But there's not many people that do that, you know, and I can't do it on my own, it's hard, you know? It is hard [laughs].

Q: It sounds you've achieved many incredibly positive things though so you should be very proud of what you have managed to do [laughs].

A: I am, I am, but sometimes it can feel a bit isolating, because I think it's because of the particular things I'm interested in, because you see a lot of people are interested in health and speech and language therapy and physiotherapy, you know, and all the therapies, and education, and work, you know, those are sort of the big things that people get locked into. But play and stimulation and activities and childcare, are not--, there's not a whole big group of people out there shouting about it, but I actually feel it's more important for Rachel, she could have all the physiotherapy in the world, you know, well number one she's not going to get it, even if I was screaming and shouting for it, she's not going to get physiotherapy every day, she's not going to get speech and language therapy every day, that's not going to happen, but she does need to be stimulated and be active to feel cared for, to feel nurtured, and to have positive experiences with the people around her. And the only way you can achieve that with somebody that's nonverbal and you're trying to get into their world is by that one-to-one engagement with intensive interaction, and we need far more skilled practitioners doing that. Sorry [laughs].

Q: I think that is all of my questions but is there anything else that you wanted to mention that I haven't asked you?

A: No, I don't really know what else to say [laughs].

Q: Well it's been wonderful, thank you so very much, well I'll end it there.

A: Okay, thank you.

Q: Thank you [both laugh].

[END OF RECORDING – 01:27:08]