



Speaking for Ourselves: *An Oral History of People With Cerebral Palsy*

Joan Ross
Interviewed by Samuel Burch

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Interview Summary Sheet

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Tape 1 Side A [Track 1]

Samuel Burch interviewing Joan Ross, tape one. Hello, Joan.

Hello, I'm Joan. Nice to meet you.

Pleased to meet you. Would you like to tell me about your early life? What it was like for you?

Yes. Well, I was just a little girl wanting to do what all the children do, and I think it was frustrating not to be able to move around like other children. I don't suppose I really realised I was any different, until children asked me questions about why I can't talk properly and why I can't walk properly, why I was in a pushchair.

Yeah.

And then it was a breakthrough really when I could crawl.

What was your early experiences like? I mean, did you live with your parents and what was that like?

Oh yes, I lived at home. I'm Welsh originally and I was born in Holyhead, Anglesey, North Wales. And my mother realised that there was something not quite right when she saw other babies. [There was] me getting on for a year old and I was hardly moving at all. And other children were sitting up and beginning to walk and I was just lying on my back and doing nothing.

What was your parents' reactions when they found out something wrong? Were they worried or...?

Well, my father was in the army and so it was really my mum that noticed that there was something wrong. It was her that would be worried and tried to get a diagnosis...

Yeah.

... on me. And she took me to a big children's hospital in Liverpool, called the Alderhey Children's Hospital.

Yep.

And they told her in no uncertain words that I was brain damaged.

Yeah.

And that I would probably never recognise my parents and that I really wouldn't be able to do much at all – very poor quality of life. But the only kind words that the doctor said was that I was a pretty baby.

How did your parents react to that? Did they accept it or did they push you further?

Well, as far as I know I think my mum was very upset, probably fainting, I wouldn't be a bit surprised. But she had a lot of determination to do the best for me and she [looked for?] any improvement and any sign of intelligence.

Yeah.

And I think first of all she tried to get physiotherapy for me, privately...

Yep.

... but by the age of two, there wasn't a significant difference in my progress. And she had a sister living in London – she'd married an Englishman – her husband had been called up to the Second World War because it was 1940, and my dad was also in the army, so she suggested that my mum came to London with me and took me to Great Ormond Street Hospital.

That must have been quite a life-changing event for you to go to London and get the expertise.

Cos I don't... I was still a baby. But yes, Great Ormond Street more or less said I had brain damage, but they did offer treatment in the form of physiotherapy and electrical treatment. But there was no ambulance, no hospital transport and so she had to take me by public transport twice a week for treatment, all through the war.

How did... What sort of public transport then was used? Was it the tubes?

Well, buses and tubes because I lived in this area [of] north London.

That must have been quite difficult for her during the war.

Well yes, and she didn't know her way around so she used to get lost.

Did she tell you any funny stories about that time?

No, I think she quite enjoyed just sight-seeing, seeing different places. And when I was five, there was an article in *The Lancet* about a new treatment for my type of handicap. They didn't call it cerebral palsy then, but that's what they were talking about. And my consultant called my mother in to see him and explain about this article. This woman from America called Eirene Collis – she was a physiotherapist – she was having a very good result. She'd designed her own treatment for cerebral palsy, and he asked mum if she was interested in putting my name down for a consultation.

Yeah.

And my mum felt instinctively that this was the thing for me, this was the treatment, this was the answer, and so she was all for it. But the consultant called her again a couple of weeks later and said there was a very long waiting list for seeing this person and it's going to be quite difficult for me to get a consultation with her. And that made my mother and father more determined to get me a consultation.

Yeah. You said that your father was called up. Does that mean...

No, he decided to...

... join up?

... sign on for 22 years because the unemployment situation was very high.

Yeah. And, when he came back on leave from the army, that must have been a quite enjoyable time.

Oh yeah, I saw my dad quite regularly and we did visit him – he was stationed in South Wales. Yeah.

Yeah. And tell me a bit more about this treatment. Did you get it eventually, this consultation?

Well, not until I was nine. There was about a four year gap.

Did you have any schooling before that or - ?

Yes. I was improving, I understood everything that was going on and I learnt to crawl. That was the big break through because it meant that I could get around the house,

Yeah.

and I could play, and my mum found me two little friends to play with.

Yeah.

And one of them - Margaret and Norma, they lived quite near me – Norma always went on her knees as soon as she came to play with me. She crawled around just like me and Margaret spent a lot of time on her knees too but Norma was particularly noticeable for staying on her knees till it was time to go home. And I could do

anything on my knees as far as in my imagination; I could dance and everything. And I thought, well, what's so different between crawling and walking?...

Did you feel...

... Not a lot.

... independent? Did it feel like it gave you independence?

Yes, yes it did. I hadn't felt no different to anyone else because I was active. I had a very nice happy childhood.

Yeah. And did you go to school?

Yes. My mum decided that I should go to school.

What was that like?

She took it for granted that I was entitled to education like everyone else...

Yeah.

... and that it would amuse me. She wanted me to be able to read so that I could read to myself and so on. She saved for me to go to a little private school very near where we lived, but they refused to have me so she tried the local infants school that was all on one level, and they were very reluctant. The headmistress did want to take me, she was willing to have me, but the education authority weren't happy about me going and I didn't have to go to school, it wasn't compulsory. So my mum decided to go to the education offices every day to ask them when they were going to find a place for me at this school she had in mind, and one day when she went she heard one of them say, 'That Ross woman is here again', and so she said, 'Yes. And I'll be here again tomorrow until you offer me a place for my daughter at school'. So they did agree to place me in the school that she'd chosen, on condition that she came there and took me to the toilet twice a day, maybe more, fed me at lunch time; the teachers would

teach me but nothing else, no personal care. But she was willing to do that and I was very happy there.

What were your memories of the school?

Well I made a lot of friends. It meant that I had children... My friends lived near me so I went to their birthday parties and they came to mine, and I had a nice real circle of friends. I dealt with their questions, I got used to being able to explain to them why I was different from them.

What was the story that you told them about why you were different from them?

Well I just said I can't walk but I can crawl because my knees were my feet.

Ah.

And they seemed to accept that.

Yeah. And did you have any brothers or sisters?

Not until I was a lot older. When I was 12 I had one sister.

Yeah. And did you get on well with her?

Yes. There was a little bit of jealousy between us, her and me, because she was so much younger than me. So she resented the fact that she was always the one that being told off and I never did. But she was a marvellous help to me because [I] did learn to walk in my teens and it was quite a big thing for me to go out on the street for the first time; I was very self-conscious about walking and meeting people that knew that I had... It was unusual to see me out of my wheelchair.

Yeah.

So my sister Margaret used to come with me and she used to chat as we walked along and it helped me forget my self-consciousness, and it went on from there really. When I wanted to travel by bus to places, again she was the first one to go with me.

Yeah.

And she didn't... [Others?] would have been [coughs] anxious about me falling and so on – they would see the danger of such a thing. But she didn't. She took it all in her stride.

Yeah. And when you left school, what were your plans with your...?

Well, everything seemed a bit... [things] ground to a halt really. There didn't seem to be any future for me. And it was very difficult to come to terms with really, that there was no plan for me... what to be... leave school. There had been meetings between the school and my mum and various suggestions were made. I was never at these meetings and the only thing that they seemed to come up with was some sort of training using my hands – making flowers was one of the things.

Yeah. How did that make you feel?

Oh my hands aren't good enough for any detailed work like that. I could do dressmaking – that was a major step forward – but I wasn't quick enough to compete with other people so I couldn't do it for a living.

Yeah.

So there seemed to be nothing for me. And I really had to rely on my own resources to find a life for myself and see what I could do. At least I'd be leaving school. I had the time...

What -

... to find out what I could do.

And what did you find out?

Well I set myself a reasonable task. I thought the best thing to do really is to improve one of the things I could already do.

Yeah.

I was learning to walk. I stood up for the first time when I was 12 as a result of the treatment that I had...

Yep.

... and I understood the treatment very well because my mum was always talking about it, so I knew how to help myself, and I developed my strength in walking. I began to go out and about on my own, and I was a member of Girl Guides so there was quite a good social life with them, including holidays and camp, and also I joined a church so I [attended?] church activities...

Yeah.

... and had a lot of friends. I was going out every evening of the week really, somewhere or other.

Yeah. And so did you enjoy the Guides and the church?

Oh yes, that was wonderful because they really made me feel like a normal person and expected me to [do] the same things as all my friends. So that gave me a lot of confidence and a lot of social skills, and I ended up with my own Brownie pack.

And so that was your main leisure activities, was it?

Yes, that was like my major work. I wasn't employed but I was doing a lot of voluntary work. My Brownie pack became a full-time job because from one week to

the other I was preparing the meetings or I was doing the next meetings and so on, thinking of ways of doing things with them.

And you said you went on holidays with the Brownies?

Yes...

Was that like camps and stuff?

... not in the beginning, but after a few years I did start taking them. We didn't actually camp. The children – Brownies – are between the age of eight and 10 so they didn't actually camp, but we stayed in accommodation. And I did about four pack holidays with them, and the children responded to me very well. They accepted my disability, they were very respectful. I had no trouble disciplining them...

Yeah

... and they were lovely, and that gave me the idea that I wanted to be a teacher.

And did you follow that? Were you able to study to be a teacher and work with children?

Well I tried. I didn't have any school qualifications, I didn't have any GCEs, so that was the first thing. You had to have five O-levels to go into college to train as a teacher, so that was my first goal – to go to evening classes and gain some GCEs. And that took a lot of... I needed the confidence really to do it. It was a major thing...

Yeah

... because of my writing difficulties and whether my writing would be clear enough for exams and so on. But I decided to enrol for a class in RSA Stage One English at the Royal Society of English.

Yeah.

And I got that; I passed it in my own handwriting and they only gave me 20 minutes, maybe half an hour extra time. I scraped through the exam and I took Stage Two (which is equivalent to an O-level),

Yeah.

and I got that. And then I went on – I then had the confidence to try and get the GCE O-level in English, and I got that in my own handwriting, and then I went on to enrol for English literature. And by this time I needed notes taken for me so I got the idea of giving someone a sheet of carbon paper and getting a copy of their notes.

Yeah.

So that was quite successful. And I joined a group of mothers really, older students that were hoping to be teachers. They were daytime classes, and there was a shortage of teachers, so I integrated that group. But whereas all the others were doing five O-levels at once, I was just doing one at a time, so I ended up with two O-levels. And then I tried to take geography. I like geography, I love it. But I kept failing the exams because there was a compulsory question to do with maps... do things to scale... and I just couldn't use two hands, and that was a compulsory map.

Did you get any help in the exams to do this? [Both speak together.]

No, not really. The only help I got was a [?] so it would keep still for me to draw the line.

Did you get upset that you didn't get any help?

Well, it was frustrating but I knew I was good at geography and so I thought, you know, I would do it, but the map question (which was the most difficult) got most of the marks for the exam, so I failed twice because of that. So I had to give up trying for the O-level in geography.

Did that annoy you?

Well, I was upset, disappointed, but I didn't give up. I chose other subjects: sociology and British constitution and history, to make up five O-levels. But it was a struggle and somebody – one of the lecturers – pointed out to me one day that my handwriting was against me, and asked me if I would be willing to dictate my answers in an exam or use a typewriter.

And did you do that?

I wasn't confident enough to dictate, but this was a time when electrical typewriters came into production and somebody I knew had found manual typewriters too difficult to use, but I thought I'd have a go at an electric typewriter, so I hired one – there was a shop locally. So I hired a typewriter from there for a few days to try it out, and I found I could do it just typing one finger on one hand. Actually I used a pencil with a rubber on the end. And that was a major break through. My local cerebral palsy group bought me an electric typewriter.

Were you involved with the local cerebral palsy group?

Yes.

What involvement did that take?

It was called the North London Spastics' Association then. I went to their socials and so on. Yes, I was very involved. And through having my own typewriter and typing exams, I eventually passed all the exams I took. And but I could never get more than half an hour extra time. At first they gave me 10 minutes extra time. My local group challenged them about that, appealed for extra time, but they would only extend it to half an hour. But I did get five O-levels and two A-levels.

What were you're A-levels in?

English and sociology. Yeah.

And so, with those qualifications, were you able to go on and follow your teaching?

Well I tried, and before I took my O-levels I applied for a teaching training course but had a very bad experience. They wouldn't accept me on the course but they wouldn't tell me straight out that they weren't going to accept me. I waited for the interview about six months and it never came, so then my lecturers at the... by this time I was attending Southgate Technical College and I had a lot of support from the lecturers that taught me and they agreed that [I should?] become a teacher. They gave me all the support they could but they couldn't get an answer from the college, and so they suggested that I went on to do a degree course and maybe that could make it easier.

[Both speak together.]

Did you do a degree course?

Yes, I did. I went to Middlesex Polytechnic which enabled me to still live at home but attend as a mature student.

Were you still living with your mother and sister at that point?

Yeah. Yes, well my sister was married by then. But my parents were a great support. But after about two years of the course I decided not to pursue teaching again.

Yeah. Did you get drawn into writing?

Not at this stage; I'd always enjoyed writing but no, that came much later. After getting my degree I was unemployed for about a year, and then I was fortunate enough to get on a special temporary employment programme run by the government, which enabled me to work for six months.

[End of Track 1]

Track 1 Side B [Track 2]

University: you'd said you opted to do projects as well as exams?

Yes, that's right. As far as the exams were concerned I had much better conditions. I was allowed double time to do exams, I was allowed to do them in a room on my own. Most exams were three hours, so it meant that I had a six hour exam, but I was allowed to have a break halfway through.

And did this allow you to get better results?

Well hopefully yes. [Laughs]. Yes I did get a 2:2, but I found really that the projects were very hard work. For me it was a mistake to opt for projects as well as exams, but anyway I got through.

Excellent, and what did you do after you left university?

I was unemployed for at least a year. I did a little bit of private teaching. I got my job, a couple of students, teaching them English language. I taught one young boy English language, and somebody else – an adult – wanted help with his reading. So I really enjoyed doing that. I did it during the winter months when people are more interested in doing something like this than in the summer. I seemed to lose my pupils during the summer and I couldn't get any more pupils, but I kept on looking out for jobs. I went to a few interviews and some of them were better than others, but nothing very promising.

What sort of jobs were you going for?

Administrative jobs mostly. There was nobody to advise me. I went to the job centre [to see a] disablement resettlement officer, but she really didn't seem to have a clue how to help me. And so I just looked up jobs and I wrote to the Director of Social Services in Haringey and I did have an interview, which looked quite promising. Some suggestions came out of that about working with physical disabilities, and the person that interviewed me promised to get in touch if he found something suitable

for me, but I never heard from him again. And then I had a breakthrough through somebody I knew that worked for Islington Council, and she spoke to somebody there, and I had an interview in social services. And under the special temporary employment programme that was set up by Manpower Services, I was employed to work with the library and information officer of Islington Social Services. That was a real breakthrough because I felt that I was doing an interesting job; I was looking through magazines and newspapers on matters relating to disability and cutting them out and photocopying them and filing them and...

So -

... sometimes...

did...

... sending them out to different people in social services.

So the disability issue became quite an important role within your job?

Yes it did. I was very . And I didn't really know how to write a CV [curriculum vitae] and when the six month period was coming to an end and they couldn't keep me longer than that, my supervisor did help me write a CV and help me to apply for other jobs. And another step programme came into being, which was very suitable for me. They wanted to set up an advice and right centre for handicapped people in Islington in the day centre, which would deal with telephone enquiries on benefits and also lots of problems relating to disability.

Yeah.

And I applied for that job and got it and...

Was that your first full-time post?

Yes it was and it was an amazing experience.

What did you feel about it? Did you feel it was quite an achievement to have got it?

Yes, and it was ideal. I wasn't teaching but I was helping other disabled people and carers and expanding my knowledge all the time.

Would you say that disabled issues and disabled rights have become quite an important part of your life?

Yes. I went on training courses and the project was managed by the Citizens' Advice Bureau so we were able to go to their training courses as well. And the steps scheme lasted the year and we were supposed to be... they hoped that they would get more funding for it to continue but when the year was up no funding materialised, at a time when the centre – it was called ARCH [Advice and Rights Centre for the Handicapped] by the way – and it was really making very good progress and helping a lot of people, and we just couldn't abandon it because the project wasn't being funded. I had another worker – there were two workers on the scheme – the other person was disabled as well, he was called Melvin, and we decided to carry on working for ARCH voluntarily for another year. So we signed on as unemployed but we did carry on working and during that year we heard about the Greater London Council [GLC] looking for projects to fund, so we applied for funding for ARCH.

Were you successful?

We were, but I had already found another job, so I left before the funding materialised and came to work in Haringey because I'm talking about 1982, and 1981 was the International Year of Disabled People so there was a lot going on.

Did that have a significant effect on your work?

Well on Haringey where I lived, cos Haringey decided that they must have a disability organisation in the borough, and also an advice service for disabled people, similar to ARCH. And so they heard about my work in Islington and I was invited to apply for

the post in Haringey, and that's where I ended up. I worked for about 17 years as advice officer for Haringey Disabilities Consortium.

Yeah. And, at this time, were you living closely to your sister or your mother?

Well I was living at home – I never left home. My sister had married and got children by this time.

Yeah. Are you still close to your sister?

Oh very, yes.

Yeah. And you see her quite a lot?

Well, she doesn't live that near, she works full time, and we keep in touch by phone.

Yeah. How did your disability affect your job? Did it... was it...?

It didn't really, it was an advantage.

Cos you, kind of, could empathise?

Yes, and I was able to encourage other people with disabilities to carry out their goals and aspirations. People that wanted to learn to drive; I learnt to drive...

How did that -

... and I got my car.

How did that change your life all of a sudden being able to drive? It must have been a monumental change.

Well yes I have got... I was able to get around by bus, but it was very difficult and very tiring and I used to get a lot of pain sometimes. So I mean a car was a big step forward and gave me a lot more freedom and enabled me to go on holiday myself.

Where did you go on holiday the first few times?

I had a friend that was willing to come with me who was also disabled – Janet – and we had several holidays in Kent. We had invalid cars to begin with...

What's -

... so we went in them.

What's an invalid car?

It's a three-wheeled car with only one seat for one person. It was made of fibre glass. My first invalid car was electric because I couldn't manage gears, and would only do 10 miles an hour, but it was on the road not on the pavement like the scooters like you see now, so I was very limited to where I could go on a charge battery. But a few years later I got a petrol invalid car which looked the same as the electric car but was able to do 50 miles an hour, and that's when I started to go on holiday because my friend Janet had an invalid car as well, so we used to go together. And we found a lovely place to stay in Westgate in Kent near Margate; we had some lovely holidays there. The first time we went it took a lot of planning because we had to make sure we could get there in one day and we had a few days out first, to see how we could manage what we thought was a long journey – about 80 miles was quite a long journey for us – and we went to Norfolk a few times, and we went to the Isle of Wight. And then I was the first one to get a proper car, what I call a proper car because you could take passengers, so I bought myself a mini.

And what was that like? What colour?

Well a blue Mini Mayfair, automatic gears. Had to take the full driving test. It was very difficult to find an instructor. I tried the BSM [British School of Motoring] to

begin with; that was a disaster. The instructor, he just wanted my money, he wasn't really committed to teaching me to drive. And during my assessment by the British School of Motoring Special Centre in Wimbledon, I put my foot on the wrong pedal and made it accelerate and that was the end of my assessment. [Laughs.]

Oh dear, oh dear.

And after that my instructor was even worse, so I just had to pack in my driving lessons with him.

So when did you find another instructor?

I decided, I was driving their cars, learning to drive in one of their adapted cars. After that I decided to save up and buy my own car, buy it on HP [hire purchase] and adapt it and find a sympathetic instructor that would teach me to drive in my own car. And I was successful at finding a very nice instructor who was really committed to teaching me. I passed my test after the second time. I failed the first time because I found making right turns very difficult on the Mini, and the examiner recommended that I had power steering, but that was very expensive so my instructor solved my problem by moving the steering wheel knob further round the wheel and that made it easier to make right turns. And I passed my test and never looked back. I was free to go anywhere I wanted to.

That must have been a fantastic feeling.

It was.

Yeah. And so... just moving on... when did you come to start writing?

After I was... It's something I've always wanted to do anyway; I've always enjoyed letter writing and stuff - it was my outlet. And while I was working, there was always the threat of losing my job because I was working for a voluntary organisation and we were dependent on reviewing our funding every year, so I always thought well if I lose my job I'm going to write my autobiography. And I did become redundant just

before I retired and that's when I took the matter seriously; set about writing. It took at least six years.

And what stories did you think were important enough to be covered in your autobiography? What areas did you home in on?

Well, I wanted to show how difficult it was to fulfil the things that I wanted to do, because it was very difficult to persuade people to accept that I could do it, and I wanted to highlight their attitudes, the things that they said to me, the negative things that were said to me.

Do you think attitudes have changed over time and got easier?

I think it's mixed. I think you'll always find some prejudice, some barriers. It probably is easier but unless people have had some kind of experience of disability it's very difficult to get them tuned into your way of thinking.

Yeah. How do you go about tuning people in to your way of thinking then?

Well, I think by showing them that I mean business. I mean what I say, that I'm going to do it.

Yeah.

You're not going to stop me.

Kind of determination.

Mmm. Because I will show you how I'm going to do it...

Yeah.

...and going really.

Yeah. And so just thinking – have you always lived in London?

From the age of two, yeah.

And what's London life been like for someone with a disability?

I think my parents brought me to London from a very small town in Wales and certainly, even as a child, I noticed that my disability was accepted far better in London, by Londoners, than by Welsh people. Welsh people were inclined to ask, 'How is she today?' to my mum. They would never talk to me. Any questions that were addressed about me were to my mum, never to me. You know, 'Does he take sugar?' syndrome.

Yeah.

That was much more prevalent.

So in London you felt freer [more free] to be yourself?

Yeah, yeah. Even with children of my own age. Much easier.

Did you find it easy to get around (transport-wise) London?

Well not easy, I mean I was travelling at my own risk really. I did have accidents but it was my choice to take that risk. It certainly wasn't easier and there was no wheelchair access. Anyway I was getting around on my own two feet...

Walking?

... although I had my car.

Were you walking or in a wheelchair?

Yeah, walking. When I learnt to walk I got stronger and was able to get further.

Yeah. And moving back a bit, you mentioned you came to London from Wales. Am I correct in presuming your grandparents lived in Wales?

Yes, in Wales.

Do you have any memories of your grandparents?

Oh yes, very fond memories, yes.

Can you tell me a bit about them?

Well, I probably was very spoiled. My mother didn't want me to learn Welsh because I was living in London and being treated by the medical profession, and she thought this would be confusing, and with a speech impediment as well. I was interested in the Welsh language, so what words I didn't know I learnt from my grandfather. So I appreciate that. It's a very fine language.

Yeah. So what were your grandparents' names?

Owen and Maggie. But I called them [presumably speaks in Welsh], which means 'grannie' and 'granddad'.

Yeah.

Can we stop here?

Yeah. So, thank you very much Joan, today, that's much appreciated.

[End of Track 2]

Tape 2 Side A [Track 3]

And how are you?

Good thanks. Joan, can you tell me when you were born?

Eighteenth of December, 1939.

And where was that?

In Holyhead, Anglesey, North Wales.

The title of your book that you wrote is Can't Walk But Can Crawl. What year did you learn to crawl?

When I was round about three years old.

And what were the earliest signs of your disability?

Well, I think because I wasn't developing at the same rate as other babies of my age and my mum had a friend who had a baby the same year, and when she realised that she was sitting up, that I was still lying on my back at nine months old, she realised that something was wrong.

And did you have any idea of the causes of your disability?

Not until she took me to a big children's hospital in Liverpool and they diagnosed me as having brain damage. The Alderhey Hospital, Liverpool.

When did you get a diagnosis for your disability?

You mean my mum not me? [Laughs.]

Yeah, your mum.

Well, when she took me to the Alderhey. I'm not really sure of the age, probably about a year old.

What was the reaction of your parents to when they found out you were disabled?

Well, I mean the prognosis was very bad, very blunt. The doctor told her that I had brain damage and that it was highly unlikely that I would grow up to recognise my parents. The only kind thing that he said was that I was a pretty baby. He seemed to think that would help. [Laughs.]

How did your mum feel when she found out?

Well, like any parent – very upset, I imagine.

Yeah. And what was the reaction of other members of your family?

Well, I think I was born into a very loving Welsh family. I was born in my grandparents' house actually. And I was very delicate; I had pneumonia at six weeks old. But I think everybody wanted the best for me, and my mum showed a lot of determination. I think she just wanted me to have treatment and she didn't give up on me really.

In 1942 you had physio at Great Ormond Street, and you described electrical treatment and facile treatment. What were these?

Massage. Electrical massage.

Could you tell a bit more about these sorts of treatment?

Well, I don't remember it much, it was only until I was up to the age of five years old. I think I remember having straps round my legs, some sort of rubber straps, and attached to a machine. I don't think it really did me any good.

Was it painful?

I don't remember it being painful, no. And my mother had to carry me to the hospital by public transport; there was no ambulances.

And what was that like cos it was wartime. Was it difficult?

I'm sure it was for her. I quite enjoyed it.

D'you have any memories of wartime London?

Yes I do a little bit. I remember hearing the bombs, and aeroplanes flying out, I think, and of course the air-raid siren and being taken to this cellar as soon as the air-raid siren went off. Lived in a maisonette in a big house on the first and second floor.

Your father was in the army?

Yes, he signed on for 22 years.

So you didn't see much of him during the war?

Well I knew my dad; he did come home on leave. He was excused from overseas service; he had done a lot of service overseas before I was born. I was nearly born in India.

What was the reason for him being excused overseas duty?

I think.

Yeah. And what did you do when your father was on leave?

He took me out and about. He tried to give me a normal childhood.

Yeah.

I began to talk and that from about the age of two or three so I could express my likes and dislikes. I enjoyed going to music halls – there was no television – and I enjoyed the radio.

Yeah. And was there anyone famous in your father's regiment?

Yes; Andrew Cruickshank. My dad became an army instructor and Andrew Cruickshank and Jack Hawkins were in his regiment.

Were they actors?

They were actors, yes.

Yeah. And did you ever meet these famous people?

No.

No. And later you had treatment at Queen Mary's Children's Hospital in Surrey. What are your memories of this treatment?

Very happy memories. It was at the first cerebral palsy unit... there were two units open about the same time and so it was a very special place and it was very difficult for mum and dad to get me into it. I could only [go] as an out patient.

What sort of treatment did you receive at the...?

It was mainly teaching me to relax and not to do anything that would cause a lot of muscle tension, so I had to be retrained how to do things. I wasn't allowed to write with a pencil for a long time or do anything that... hold anything very tight, that caused a lot of tension and a lot of control. So I had to be re-educated really on how to [do] things in a relaxed way, and try not to dribble.

Yeah. Was that quite frustrating?

Well, I was older, I was nine when I started the treatment and I understood it so well that I was very co-operative. It wasn't frustrating. I felt that I was really going to achieve something.

Yeah. In the first tape you mentioned a physio – Eirene Collis – who was mentioned in The Lancet.

She became a specialist in cerebral palsy and devised her own method of treatment...

What was so diff -

... which was quite unique.

What was so unique about the treatment she was offering?

It was unique because she didn't believe in surgery. A lot of children were operated on and that, at that time. She didn't believe in splints to keep the legs straight. She didn't believe in callipers. She wanted to train the children to straighten their legs and correct their positions themselves, to make them aware of how it should be by using mirrors.

And...

So the children that progressed the best were the most intelligent children, that understood what the treatment was about.

Yeah. How hard was it for your mother to get you a place in the hospital?

Very, very hard. It took about four years.

What sort of campaigning did she have to do?

Well she went to her MP and he really was very influential in getting me a private consultation in the first instance. And I was treated on the grounds that my mum work voluntarily on the unit every day, and learn about the treatment. And she was one of eight mothers that did this with their children and they were from all over the country, all over the British Isles. When I was first refused treatment my parents were told that it was because we didn't live in Surrey, so we weren't eligible. But that was nonsense.

And what were the other patients at the unit like?

Very mixed. Some were older than me, some were younger.

Were there different severities of disability?

Yeah. And I was the only one that had had any schooling.

Yeah. And what sort of friends did you make there?

My closest friend was Dorothy; she was four years younger than me. Her mum and my mum became great friends. We shared a flat as well. She was from Belfast in Northern Ireland.

And did you ever get up to any mischief with her?

Not really. I think there were more boys than girls as far as I remember.

Yeah. And do you remember anything from the schooling that you received in the school there?

I enjoyed it very much and the emphasis was on reading and art, finger painting, that sort of thing. It was good for the hands, gaining co-ordination.

What did you... what were the...

And I worked a lot with clay.

Yeah. What sort of work with clay did you do?

Making ash trays and pots and things.

Yeah.

It was very good observation therapy really.

And what did you do on the weekends while you were away?

Well we used to go out and explore the local district where we lived. We lived in Carshalton. The hospital was in Carshalton. We went to church and sang there, oh yeah.

Was religion -

And sometimes we came home for the weekend.

Was -

By public transport.

Yeah. Was religion an important part of your life at this stage?

Not as much, except that I always went to church.

Yeah. In your book you mentioned that you won a competition with the I Spy book.

Was that...?

Oh yes, that was after leaving Carshalton, no, before I think... maybe it was while...
I'm not quite sure.

What were your memories of winning the competition?

Well we had a visit from Big Chief I Spy, in his Red Indian costume. So yes, that was quite a surprise. He turned up unannounced really to give us our prize in person.

What was your prize?

It was [inaud] telegraph. I don't really remember. It may be a package of things. I don't think it was a particular one prize.

How did you feel about the fact that schooling for disabled people at this time was not compulsory?

Well I was too young really to appreciate that. I did go to school – my mum had a fight to get me there and I enjoyed school very much.

What was the name of your first school?

[inaud] Infants' School – a local school.

How big was it?

Quite a small school. It had about eight classrooms.

What were your memories of it, good and bad?

Oh they were all good really memories because I had some nice... the headmistress chose two or three girls to keep me company at playtime. I didn't go into the playground except with my mum at lunchtime. During the other times these girls used to push me round [in the pushchair]. There was a quiet part of the school where there were gardens and we used to spend playtime there, chatting and things.

How did you feel about using a pushchair when you were at school?

Once the children accepted me in my chair, didn't call me baby, I was fine about it.

Yeah. And, what were the other children's reactions to it?

When they first met me they always asked the same question: why am I in a pushchair? Why can't I talk properly? And my answer was I can't walk but I can crawl, because to my mind my knees were my legs and that's why I called my book *I Can't Walk But I Can Crawl*.

And was it at this stage that you first learnt to crawl or was it earlier?

Oh no, much earlier, at the age of three.

Who was your first teacher at this school?

Mrs Ilkley.

Do you have any memories of her?

Well, I remember her as a very kind motherly lady who told wonderful stories; I loved story time.

And was it at this stage that you met your friend Margaret?

No, Margaret lived in the same road as where I lived and my mum found her for me and she used to come to play with me, long before I went to school. We went to Sunday school together.

Do you have any memories of Sunday school?

Yes, I enjoyed it – I enjoyed singing and the stories again. Yes, I enjoyed it.

And do you have any memories of good friends at school that helped you around?

Do you mean in my first school?

Yeah, your primary school.

I think the best bit about going to a local school was the fact that it was in my neighbourhood, so I had friends in my own neighbourhood, near where I lived. So I was invited to their homes to their birthday parties and they came to my birthday party.

Do you have any memories of birthday parties?

Well, obviously the games and things as I got older, yeah, planning them. Margaret, my friend, used to help me organise the parties as I got older.

What were your later school experiences like?

Well, from after I went to a school within Queen Mary's Hospital, where the cerebral palsy unit was, and then when I left Carshalton I went to a specialist school called Vale Road School for Physically Handicapped Children.

And what were your memories of that school?

Very happy. There were all sorts of children there. I met a couple from the time that I was in Great Ormond Street Hospital outpatients. I was reunited with one special friend after joining the school. She's called Sylvia, who's a year older than me, and a very determined person even at that age. She was less disabled than me but she inspired me by the way she was determined to do things to help people and anything she wanted to do, she found a way of doing it. She was also very mischievous and she had a friend called Margery. They had me in giggles because of the antics they got up to.

Yep. And d'you have any memories of holidays that you had when you were younger in Wales?

Well, yeah. I went to stay with my grandparents during the big holiday in the summer. So I have lovely memories of the beach – crawling on the sand, crawling into the sea

and, yeah, having a lovely time. And my mum had a friend that had a daughter the same age as me and they lived in London, so they used to come to Wales during the school holiday and the two families stayed with their respective grandparents, so we met up and we spent a lot of time together. Her name was Pat. Played a lot with Pat in the summer holidays on the beach.

Yeah. And do you have any memories of your grandparents?

Oh yes, very much. They were lovely. Idolised me, spoilt me. My granddad taught me a little bit of Welsh. My mum didn't want me to learn Welsh.

Why was that?

Because I lived in London. But my granddad did teach me quite a bit of Welsh. Welsh songs and so on.

What was the house like that you lived in when you were young?

We lived in a maisonette with my auntie, so it was on two floors and there was a lot of steps to the front door from the pavement – I had to be carried. And then another flight of steps and then about five more stairs to get to our living quarters, to get to the kitchen and living room, and steps to the toilet and bathroom so it was very difficult for a disabled person really.

How did your... I understand you moved in to a ground floor flat in 195 -

Fifty two.

How did your life change after that?

Greatly. It's this very flat, and it was when my sister was born, when she was a baby and we moved here. And it's much more on the level. Where I lived before was on a steep hill. So, because of the treatment I had I was beginning to stand and walk, [it] is

flat, because it was on the level, greatly contributed to me having the confidence to try and walk, and eventually venture out of doors, cos it's level outside as well. No hills.

What was your daily routine like at this stage?

Well, the coach used to pick me up to take me to school every morning about half eight, and I used to come home about half four, tired and hungry, and that was about it really.

When did you learn domestic tasks like ironing and, and making tea and needlework?

Well, because I was leaving I started needlework at school and a little bit of cookery. After leaving school I developed those skills at home because I was unemployable and so I set myself challenges to do things, to regain independence and to be useful at home.

How did these independence skills influence your later life?

Well, really it I felt very abandoned after leaving the protective environment of a special school. There didn't seem to be anything for me. It seemed to me as if my life had come to an end. So really I had to do something to motivate myself, and it was a very depressing time really until I started thinking well, I'm going to set myself a challenge, find a challenge, try to do some [something?]. Sometimes it was quite a significant thing, like being able to thread a needle, and other times it might be something quite stupid. [Laughs.]

So was the key reason for it a motivation factor?

Yes, yes. I wanted to be normal really.

OK. And you had a sister...

Well, she was a baby.

Yeah.

She was...

How did having -

... still very young, even when I left school.

How did giving a sister change your life?

Greatly because she was a companion and she was very lively as well. And when I started to walk out of doors she must have been about four or five and she didn't mind coming with me, and that was a great help to me because I was a bit self-conscious when I first started walking out of doors; I was a bit scared of meeting people that had always seen me in a wheelchair. I was afraid of their reaction, and having a little girl with me who was very chatty and chirpy sort of took my mind off that, and she enjoyed being with me. And it was through her that I learnt to go on a bus, take bus rides, because she didn't see any danger in taking me on a bus – she would have been about seven or eight by this time – but my mum flatly refused to come on a bus with me, walking, but my sister didn't mind. And I gained a lot of confidence through having her with me.

What were your memories of the period running up to your sister's birth?

Well that was difficult because I had to be sent away from home for the first time because my mum was scared of having another disabled child, so she wanted the best possible medical care and that meant going into hospital before the baby was born. We're both Christmas babies so it meant that she was in a hospital, mum, and I was sent away for eight weeks, which seemed like a lifetime.

How did that make you feel?

I was dreadfully homesick and for the first time in my life I didn't have the freedom that I had at home. I was asked to stay in my wheelchair all the time; I couldn't crawl

around. And I had to wait for somebody to take me to the toilet. Anything I wanted, someone had to do it for me, and I was used to crawling around and getting what I want.

And how did it feel not being able to stay with your relatives and having to go into a home?

Well, I think I understood that it was inevitable but, yes, it was pretty awful really, specially in the middle of winter and having to be away for Christmas and my birthday. So yes, it was awful really.

In your autobiography you mention the church, and Guiding as quite an important social outlet for you. When did you first join the church, and what social opportunities did this present?

Well, the Guide company was a...

[End of Track 3]

Tape 2 Side B [Track 4]

... to mix with girls of my own age near to our home. We had a uniform which made me feel one of them. Our school didn't have a uniform so I enjoyed having an identity. I enjoyed the badge-work in Guides because that was way of proving myself. We didn't really take a lot of exams and that at school, so this was a way of stretching myself and proving myself. The Guides, once they realised that I was just the same as them, except I was in a wheelchair, accepted me and I really felt one of them.

You came to run your own Brownie pack. How did that come about?

Yes. That was after I left school. I was still in the Rangers, the senior part of the Guides, and one of the things the Rangers did was help with Cubs and Brownies, so I was delighted when I was asked if I would like to help with a Brownie pack, and I did that for about a year, or maybe longer. And then my own church Brownie pack was without a leader and I longed to offer to take over the pack but I didn't want to do that because I didn't want to be turned down. So I was delighted when I was approached to actually do that, and I did it for 15 years. And it really compensated for not working because it gave me an important job to do which took a lot of time but was very worthwhile.

And you took the Brownies on holidays. What were they like?

Yes that was towards the end of my 15 years. I didn't do that when I first took over the pack; probably during the last five years when I was leader. Yes that was wonderful. We went for a whole week. I had other Guiders to help me but I did all the planning of the activities.

You were also involved in the church. When did that kind of take place?

Well, during from the age of 12 really. In my twenties I helped in Sunday school...

Yeah.

... as well.

Would you describe religion as an important part of your life?

Oh yes. It gave me a faith, so I felt that the power of prayer is very relevant to me. People were praying for me and that encouraged me, and I think their prayers were answered.

OK. [Rustle of papers.] Sorry. Can I just move on to your later education? You took your exams after everyone else. When did you take your O-levels?

Well, it was my own initiative really. I felt that I was really making good progress physically, had a good rapport with children, and I decided that I'd like to be a teacher, and that I would like to teach disabled children. And I was lucky because there was a campaign going on at the time to attract mature students into teaching. They wanted mothers who had got their children off their hands and would probably go into teaching. So there were day courses run by the adult education authority in my borough, and I managed to join those classes at... But before that I went to evening class to just have a go at trying to get an O-level in English, and that took three years to get because I took other exams first. But that led on to me getting five O-levels in the end, GC O-levels, and then two A levels. I thought the five O-levels (which was the standard requirement to get into teacher training) would get me in, but unfortunately I wasn't accepted for teacher training because of my disability, and that was very disappointing.

What was it that made you want to become a teacher?

Because I felt I could do it.

And what -

I like children, they like me. I gained respect from my Brownies.

What was the experience of doing your O-levels and A-levels actually like?

It was very hard because I could only take on one at a time, and so I did by going to classes quite near to home. But then I went on to travel further. I joined Southgate Technical College, which is about three miles from my home. It meant travelling on public transport, which I could now do. It meant using a tape recorder to tape record lectures and make notes from them.

And why was it that eventually you chose not to pursue teaching?

I wasn't allowed to.

And how did that make you feel?

Terrible. I was very angry and it was a shock because I had such a lot of confidence; I thought all I needed was five O-levels to get on the course and I didn't consider my disability as a barrier. But everybody else did except for a very few people that encouraged me and fought for me, without success.

And do you think that was a manifestation of the negative attitudes that you encountered?

Yes. I really came to the conclusion that... because I went as an observer to a school at the suggestion of the principal that interviewed me for the teachers' training college that I applied to first. I went once a week to a school to observe what was involved in teaching, and I realised that the headmaster gave a very negative report about why he thought I couldn't make it as a teacher, and pointed out the things I wouldn't be able to do, and then I realised that teachers didn't want to admit that a disabled person could do their job. I'm sure that was the hardest thing for them to do.

Mm. Later on you chose to do a degree. What was this in and what was the study like for it?

It was in English and History. First of all I thought that might get me into teaching so I chose English and History. I found it much easier than the former studies; I got

much more help. By this time I was able to type on an electric typewriter, and when it came to actually sitting the exams for the degree I was allowed double time to take the exams whereas for my O and A-levels I was only allowed half an hour. That was after a long negotiation – they wanted to give me 10 minutes extra time at first – so to be allowed double time for my degree and allowed a break during the exam, because a three-hour exam would take six hours, it was just fantastic. And I gained a lot of support.

What effect did that have on your confidence and self-esteem.

A lot of confidence and I really enjoyed it. The other students were all very supportive. I just was one of them.

Later on you got a job as a social worker.

No.

No?

No. Never a social worker. I worked for Social Services...

That's it. Sorry – Social Services.

... for the Information Officer.

Yeah. And how important was this advice work for the disabled community, do you think?

Well, it led to doing advice work. The first job was actually collating and collecting information for social services. I had somebody supervising me who was a librarian and information officer and I learnt a lot from him.

And do you think this work was important, kind of as a reference point for the disabled community?

Well it was because it was at a time when disability was becoming on the public agenda. There was more public awareness because in the 1970 Chronically Sick and Disablement Act – Disabled Person's Act – that meant that there was much more provision for people with disabilities, from their own councils.

Yeah.

And then we were approaching 1981, which was the first International Year for Disabled People, so it was good time to get into working in a disability field.

If you were to reflect on your life so far, do you have any major ambitions still, or any regrets from your time?

No. I'm pleased with how my life has turned out; I think I've had a very rich experience of life which I hope that I can pass on the benefits to other people, and especially from my book.

What social opportunities have been available to you in adulthood?

Well, only from my own efforts really; I think learning to drive, which was a major contribution to leading a normal life socially and being able to go on holiday independently, just with a friend.

So do you think driving has affected your later social life and made it easier for you?

Oh I really couldn't have done anywhere near as much without being able to drive. I probably couldn't have worked without being able to drive because public transport was fine for a little while but then there were difficulties because I was getting older.

Yeah. What was the major motivation for writing your autobiography?

Cos I want to share my experiences with other people. I also want to educate professional people because I have suffered from their ignorance, and I want people to

know what it's like to be disabled and the ridiculous barriers that people put up against disabled people, through ignorance.

And do you think you've achieved that with your autobiography so far?

Well, I'm trying to. It depends on how well it will sell.

Yeah. Well is there anything you'd like to add at the end to kind of... that hasn't been mentioned so far?

I think you've covered most of it. It's an abridged version of my life. [Laughs.] It's very much abridged. There's a lot I've had to leave out, but I hope that will inspire people to read my books.

OK. Thank you very much, Joan.

Thank you.

Joan, how excited were you when you actually finished your autobiography?

Well I can't believe that this pile of loose papers that I've been going through, because I've had to proofread it so many times, I can't wait now to see it, the actual book form bound together. It's taken me at least six years to write, maybe longer. It's been very hard but when the book is finished then the real work begins because it's got to be proofread so many times. I've used an awful lot of photographs that are very valuable I think to my book, but it has been hard work making sure that they match the right chapters and the right headings are put with the photographs. That's been quite hard work.

Do you consider it the major achievement of your adult life?

Well that remains to be seen. I think it's too soon to say that, but it's something that I'm glad that I had done because I've always said I wanted to write my story.

And what was the name of the book again?

I Cannot Walk But I Can Crawl.

And who is the publisher?

And it's got a sub-title: 'Living with Cerebral Palsy'.

And the publisher?

Paul Chapman Publishing.

Right.

In association with Scope.

Thank you.

[End of Track 4]

Tape 3 Side A [Track 5]

Sam Burch, interviewing Joan Ross, tape three. Hello, Joan.

Hello, Sam.

If we could start talking about your later life and your time at university.

Yes.

Were there any access issues at Southgate Technical College?

No, no. I was quite mobile and there were stairs and everything but I did get around the college quite well. It wasn't that big so I managed very well.

And can you remind us; what was your degree actually in?

My degree was in Humanities – English and History.

And what were your memories of your degree studies and the fellow students that you were with?

Well, first of all I was delighted to be accepted on the course and there was no battle like there had been in the past - I was accepted no problem. And when it came to taking exams I had all the help that I needed, and that was a major breakthrough and made life a lot easier for me.

And do you have any memories of your fellow students?

Oh yes, lots of memories.

Could you tell us about them?

Well, there was quite a few mature students, some older than me, some about my age, as well as those that came there straight from school, so it made it quite easy for me to integrate on to the course. They all seemed to be anxious to give me all the help I needed, without smothering me. One of the interesting things about it was I learnt my way around fairly quickly because I didn't want to walk further than I had to, so I got to know my way around quite quickly and I found myself showing other people the way to get to certain buildings [laughs]. We helped each other in that way.

In your book you mention a person called Phil who was -

Yeah.

Could you tell us about your relationship with Phil?

Well, he was one of the younger students. I met him on the day of my interview six months before the course started, and I think we were somehow drawn to each other. We were both very nervous and we sort of stayed together; we were there the whole day and we went to the building where the interview was and also we met actually in the refectory early on in the day and I never forgot him. And when the course started I was pleased that he was on it and we became very great friends.

And in the book you mentioned you went and saw him in York?

Yes. I was very excited when he invited me to his home in York. I went several times. I think I probably fell in love with him but I was very conscious of the age gap between us, and that made it very difficult for me to develop the relationship but I suppose I attached myself more to him than any other previous relationship.

What was the reaction of the people around you like your family and friends?

Well, I think my family were a bit surprised and probably the old fears of they didn't want me to get hurt, etc. But I put all that aside and I wanted to share my time on the course with Philip both socially and academically. He was a very good friend, a very good listener and also very supportive when I needed a bit of extra help to carry

things and get around. He was always there for me. But all the students were committed to helping me and I think it drew the whole year closer together because they all were committed to helping me.

OK. And what were your feelings when you graduated in your degree?

Well, it was just wonderful that I'd achieved a degree; something I'd never imagined because it was a decision that I made quite late, and I hoped very much that it would lead to employment, not necessarily teaching but I wanted to work in the disability field.

Why was that? What drew you to the disability field?

Well, my own experiences. I would have liked to have done a research degree, a master's degree, centred on disabled children and the isolation that they have. I wanted to prove how important it was for disabled children to integrate and so I was disappointed that that wasn't possible because I didn't have a first class degree, so I wouldn't get any grants towards the study.

And what do you particularly remember about your early work?

Well, I was unemployed for at least a year, perhaps just over a year. I was very disappointed when I went to the job centre and saw the disablement resettlement officer, who I thought would be very helpful in finding me work and advising me, but she was extremely negative and I got nothing at all from the interview except a green registration card with a number. So I was very disappointed but I found out later that you get more help from the DRO, as they're called, when you've actually found work. They can help you with equipment and travelling expenses and adaptations to the work place, but I needed to find a job.

When was the first breakthrough that you made in finding a job?

Well, it came really quite unexpectedly from a neighbour who worked with Islington Council. She had a slight disability herself and she spoke to her colleagues about me

and they were interested and I got an interview with the Social Services Department in Islington. And there was a government programme to help people get employment called Special Temporary Employment Programme: a step resort. And it would enable employers to take me on for six months and the government would pay towards my salary. So I got my first job assisting the Information and Librarian Officer at Islington Social Services.

And what were your memories of the colleagues who you were working with?

They were all very friendly and very supportive and the person supervising me – the, the Information Officer, Ken – he helped me to write a CV [curriculum vitae] so that I could apply for other jobs. I didn't even know how to write a CV until he showed me what to do.

And you got a job later in an organisation called ARCH [Advice and Rights Centre for the Handicapped]. Could you tell us a bit about that?

Yes. That was another temporary employment programme, and this time it was to employ two disabled workers. They specifically wanted workers with a disability to set up an advice and rights centre for the handicapped, and it was called ARCH and it was set up in a day centre in Islington with our official office, which was equipped by the employment service, and it had a year's funding to start with.

Who were you working with and who was working alongside you at ARCH?

Myself and Melvin Kinnear - another disabled person who had a spinal injury. And he was lot younger than me and we worked together assisted and supported by a management committee made up from users of the day centre.

At this time your parents were growing older and their health deteriorated. What was that like balancing work with helping them?

It wasn't so bad at that time. It got much worse later. But I was beginning to take on more in the way of helping them by being responsible with shopping, etc.

Yeah. And you learnt to drive a four-wheeled car. Have you got memories of your first...? [Both talk together.]

Yes. I had an invalid car to start with and that helped me to understand the behaviour of other drivers and understand the highway code etc., and that gave me confidence to take driving lessons and get a four-wheeled car. But it was very difficult to find a driving instructor to begin with.

And what do you remember about your first Mini?

Oh it was wonderful, I was very proud of it. It was new. It was a big chance getting it because it would mean giving up my invalid car. I was only allowed to keep the invalid car for six months in the transition period, so if I found [by?] giving up the invalid car that I couldn't drive a four-wheel car, then I would be stuck for transport. But luckily I succeeded in eventually finding a second driving instructor who was very committed to helping me pass my driving test. And that opened a whole new world to me.

Were you in any way scared when you first started to drive your Mini?

Well, I suppose I was anxious but the instructor was very supportive and very relaxing to be with and very patient with me, so it did help me lots to overcome my difficulties.

And can you tell me; when was it that you moved to Haringey Disabled Association to set that up?

Well I couldn't get any more funding and we decided, both of us, to carry on the work on a voluntary basis and we were paid as volunteers from Islington Social Services because that wasn't a salary, it was just enough to cover our travelling expenses to get to work. And in the meantime there was hope of ARCH getting funding from the DLC, but before that came through I was offered the same kind of work with Haringey Disablement Association, which was a new organisation.

What sort of work was that involved in?

To begin with it was very similar to what I was doing: finding out the means of advice and information work and getting ourselves known in the borough. Again I was one of two workers but this time it wasn't full-time work, it was a job-share; two and a half days each.

Who were you sharing with?

With an able-bodied young lady, more or less fresh from university.

What were your memories of the colleagues who you were working alongside?

Well, I felt a bit threatened working alongside an able-bodied person because she was so dextrous with using the phone and making notes, and she was so quick at everything that I felt I was dragging behind. But I realised that I had much more knowledge of disability benefits and other issues from my own experience and through working with ARCH that I came to realise that that compensated for my physical disability.

And do you think that was an advantage?

Yes it was.

In the book you talk about a small corner, and was this at this time when you were working with the Haringey Disability Association?

Yes. That's how I looked at my office from my religious point of view really. I think we've all got a part to play in this world so my office was my small corner where people came to me for help, advice, support, encouragement.

Yeah. Was it at this stage that one of your colleagues decided to go out on strike for support of other workers.

No, that was in ARCH.

Was it in ARCH? Oh, I'm sorry. Could you tell us a bit about that?

That was rather funny. I think the book would describe it much better than I will.

Just have a go for the tape.

But basically there was a one-day strike by council workers and Melvin went to the pub the night before this strike and got talking to other people obviously about this strike, and when I came to work as usual next morning he wasn't there at his usual time. And as time went on, the phone went and he rang me to say that he was on strike, which seems very funny now, but at that time I was very cross because we weren't in the union so we had no right to go on strike.

Did you feel put upon at that point?

Well, I just felt cross with him because I felt that we were both trying to prove ourselves as group workers, that we were employable. That was the most important thing for both of us...

And...

... and so to go on strike would be against... it was [?] to our reputation, and we had no grounds to go on strike because we weren't in the union.

How did you make your feelings clear to him?

I gave him a good telling off. [Laughs.] Eventually. I wouldn't speak to him at first but I think he knew how I felt and he probably came round to my point of view in the end. I gave him quite a hard time the following morning and it was OK.

Did that incident strengthen your political views about striking or - ?

Well, not that particular incident, but I did meet people with disabilities that lived [in] Islington but were quite militant about their rights and issues, which taught me a lot really because I'd never come across people with disabilities as militant. My experience of people with disability were that they just accepted everything as inevitable, so it was good for me.

Did you feel threatened when you first met the militant people?

No, not at all. I admired what they were doing.

And could you describe to us your involvement in the North London Spastics' Association, later to become The Cerebral Palsy Association?

Yes. It was like the Spastics' Society itself, an organisation for parents of children with cerebral palsy, because they needed support and advice. But that had changed because after the International Year of Disabled People the disability movement grew and became in the forefront of getting things done for themselves and that included running their own organisations. And so the North London Association had less and less parents involved; it was run by people that were working in the disability field but had no other connection with disability, and I was the only member of the committee with cerebral palsy to begin with. I don't know how that happened, I can't remember now. But as time went on I was more and more aware that the organising wasn't being run in the way that the political movement was going and it was time that people with cerebral palsy got on the committee and ran their own organisation.

What was your involvement in changing the way the organisation was run?

It was very difficult at first. I became chairperson of the organisation; that helped a lot. But the other members of the committee didn't really want to give me too much control. They wanted to... they were control freaks. They'd been in the organisation for so long that they didn't want to give that power up, so they gave me quite a hard time. I was concerned that they were giving grants to people in the association and I

was concerned at the lack of confidentiality in discussing individual people in such a large committee.

What did you have to do to change attitudes?

Well, I'd chairperson, and with the support of my colleagues in the Haringey Disability Association I began to realise... I was encouraged to take action and set up a subcommittee of committee members of five or six people to discuss grant applications in a more confidential way. But the meeting had to include the Trader Association, who's a bank manager, and the committee decided to have these meetings at his office in Swiss Cottage, and I worked in Tottenham, and the meetings were arranged at 5:30.

Was that done specifically to exclude you?

To stop me coming because I wouldn't be able to get there in time. It's a long way from Tottenham in rush hour. But I managed to reconvene the meeting at my work place. And when these people found that I was assuming so much power most of them resigned. And at the AGM [Annual General Meeting] the committee was overturned and it consisted mainly of people with cerebral palsy and we got ourselves a new treasurer.

That was a significant victory, then.

Yes.

Yeah. Can you reminisce a bit about your memories of the International Year of the Disabled People in 1981?

Well it was very exciting because the media included a lot of programmes on disability, which had never happened before. You never heard much about disability on the news or any other programmes. And for the first time there was a lot of documentaries on individual people with disabilities, including people with cerebral palsy. So for the first time disabled people were in the public eye.

And this was obviously a good thing.

It was, because at last we were recognised as part of the community and my past experiences... I was meeting people that were nervous about how to talk to me, how to help me, so we needed these programmes to educate people. But of course you have to be interested in disability to watch them in the first place, so how many people did, I don't know. But it gave me a lot more confidence in the population's attitude.

So awareness expanded?

Yes.

Yeah. How did your role in the Haringey Disability Association change over the years?

It changed in the fact that we became more professional in our work. My work in ARCH was only by telephone; we didn't actually have in-office interviews, but we started to introduce that in Haringey, so more and more people came into the office. The benefit system changed a lot anyway and there was a lot more form filling and people needed to come into the office, either people with disabilities themselves, or their carers. And we had to use interpreters a lot.

What were the interviews actually like?

They were all very different according to the disability. Some were very complex and it took a lot of ingenuity to prove the need for benefits. The forms got longer: they started by being one page but the later ones were 36 pages long and it could take up to four or five hours to fill in.

Yes.

Well you can't do more than one interview. And when you have people with speech impairments it took even longer because it was very important to present the difficulties of that person and the kind of help they...

[End of Track 5]

Tape 3 Side B [Track 6]

... The Haringey Disabilities Association and how your role changed. If you could continue.

Yes. Because the benefits changed and the forms for the main benefits first were only one page then, and then they were 36 pages long, and I was trying to present a true picture of the disability and the amount of help people need with their care, mobility, and it could take as much as four to five hours to fill in these forms, especially if somebody had a speech impairment or writing difficulty as well. I used to have to use volunteers to help me with the writing. We also had to use diaries; I used to encourage people to use diaries. So a lot of the benefit claims were quite a challenge, but my experience grew and I became quite successful...

In your book you -

... and I used to go to tribunals with people.

Yeah. In your book you described your frustration later on at how the paperwork and the bureaucracy took up more and more space and there was less room for interviews.

Yeah, that's true. It became very important (according to the manager of the organisation) to keep statistics.

Was that frustrating for you?

Well it took up a lot of time because I never did work full time. My hours were extended to 21 hours a week. That meant three whole days and so the more time spent on paperwork, the less time I had to deal with people and their claims.

Did you find that frustrating that you weren't able to help people?

I did. Somehow I managed it, it just took longer. And I was very committed to proving that the service was needed, and the only way to do that is to provide statistics.

Yeah. If I could just move on and ask you a bit more about your parents' health because when you were working for the Haringey Disability Association your mother and father were growing older...

Yeah.

... and your role with them changed. Could you tell us a bit about that?

Well it was a slow process. First my mother was diagnosed with diabetes and she also had arthritis. She had to have a hip replacement and after the hip replacement her knees started to trouble her, so about a year later she had to have a knee replacement. But the second operation affected her diabetes more and she became very forgetful and confused. And my father at first was very good. He looked after her and was very strict about her diet – the sugar-free diet – but then his mental health deteriorated and really he got to the stage when I was afraid to go to work and leave them because they let in some con men into the flat one day and didn't realise the seriousness of what happened. And after that I tried to seek carers out; to get carers to look after them while I was at work and it proved to be very difficult to get the help from Social Services and also to convince the medical profession and Social Services that they needed to be supervised while I was at work.

Did you manage to get carers eventually?

It took nearly two years altogether, but I did get help from the Independent Living Fund for my mother only, because her disability was the most profound. But when the help came the hours were so limited that it was only like 14 hours a week, so I had to use that time for carers to be here on the three days that I worked, and it meant that I had the sole responsibility for them over a long weekend from Thursday to Monday morning, which meant I could hardly leave the home, had to be with them all the time to supervise them and make sure they were safe.

Did you get any help from your sister?

A little bit but she lived nine miles away and her children were too young really; she was taking them to and from school every day. So she mainly did the hospital appointments and tried to come over once or twice a week to fill in some of the time that had to be covered while I was at work.

Yeah. How did your father's health deteriorate after your mother was taken to hospital the second time?

Well, he didn't really understand what was going on. I don't really think he had dementia, I think it was severe stress that caused his behaviour to deteriorate. He couldn't go and see mum on his own, she was some miles away. He had to be taken to see her. But when he came home again he'd forgotten he'd been there so I had a lot of trouble keeling him indoors, he just wanted to be out all the time and he'd try to get to see her. And because there was a little hospital opposite where we lived, he thought she was there, so he was constantly going out and trying to get to see her and putting himself in danger with traffic etc. cos this is a very busy road.

Yeah. In your book you mention about a carer called Italia. Was she...

Yeah.

... was she involved at this stage?

She was one of our first carers so yes, she looked after my parents from the time when my mother had her hip replacement and yes, her hours were increased as part of the care package and she proved to be a wonderful help.

What was it like becoming an aunt to your sister's children?

It was wonderful because I never had children of my own...

Yeah.

... so my sister tried to share her children with me as much as she could. I saw them as often as I could and yes it was a wonderful, great contribution to my life.

And now, you went on holiday to visit a friend in Canada. Can you tell us about that?

Yes. She was one of my oldest friends; I first met her when I was a Girl Guide. She emigrated when she got married at the age of 21, to Vancouver, and after my mum died and my dad was settled in a permanent residential home I felt free for the first time for quite a few years, and so I always wanted to go to Vancouver so I was very fortunate to be able to go and stay with Jill and Bob for three weeks. I took my friend Francis with me as a travelling companion and a help to look after me while I was there, and it was wonderful holiday...

What did you do while you were -

... one of my best.

What did you do when you were out there?

Well we did a lot of sightseeing, all the usual things. Jill's husband had taken early retirement so he was our chauffer and guide. We went to see [?]; Francis and I went to see [?] on our own for a couple of days on one of the weekends, and we also went to Vancouver Island. So we saw a great deal of that part of Canada.

Great. Describe the process of writing an autobiography and what it was like to recall memories in writing and in these recordings. What's it been like for you?

It's been good but I think it was invaluable to attend a writers' workshop. I'm very glad that I did that because I think I had very good tuition at the City Literary Institute in Holborn. I was encouraged to write pieces about my life, not necessarily in chronological order, so that made it more interesting in a way because I could write whatever I felt like. I could write something about my childhood one week, and the

next week write something that happened a few years ago. It was only when I'd finished that I started to edit it and make it onto an autobiography. So it was very enjoyable and a very good way of doing it.

What would you say your major observations are about disability and what you would like others to know about it?

I think we need to get over to people that we are an important part of society, that we do have the same feelings and desires that they have, and that we should be allowed to explore our own potential. We should be allowed to make our own mistakes because that's what everyone else does. We shouldn't be overprotected. It can be very hurtful, it can be very frustrating. But I think that every disappointment that I've had has taught me something about myself and how to deal with it.

Who have been the most influential people in your life?

I've got some very good friends, apart from my family and then of course my sister, who's been a great help and I suppose she is the closest person to me. And, being a lot younger than me, she took the young point of view; she didn't have the same fears and protectiveness that older people would have, or even people of my own age. But I've also got some very good friends who believed in me and encouraged me.

What do you feel about your personal life in adulthood?

I'm pleased that I've been able to do the things I have, that my parents allowed me to go out and about. It must be worrying for them. I've realised that as I've got older and I'm appreciating the fact that they must have watched me go in my car in to the traffic and it must have been quite frightening for them. But they allowed me to do that and that was important to my development as a woman.

Yeah. What would you say to a younger Joan if you were going to give her some advice?

Let me think about... I think, again, to follow your own instinct and be prepared to make mistakes, be prepared, and be responsible for the consequences of what you try to do. But to go for it, not shut yourself away.

Just the last question now. What is the detail or the main message that you would like to get through in your recordings and through your autobiographies? What's the detail of the message?

I think the theme is life itself. The fact that I wasn't aborted as a baby, that I was allowed to [be] born and that my disability was catered for and to live life to the full, that's my message, that life is important. You can't destroy life, you can't destroy people, mentally or physically. Life should be lived to the full. It's an abundant life. It should be that, however disabled you are, you should get all the help you can get from other people and use your own resources to live life to the full.

Is there anything else you'd like to add before we finish?

That's it.

OK. Thank you.

[End of Track 6]

[End of recording]