



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

Dorcas Munday
Interviewed by Philip Mann

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Interview Summary Sheet

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Tape 1 Side A [Track 1]

Right, and so, Dorcas, it's the 23rd of June today – nearly July, and could you tell us first of all Dorcas, when and where you were born?

I was born in Northampton General Hospital in what they called Barratt Home, which was the maternity block at Northampton. I was three months premature – I should have been born in the September and I was born in the June – I weighed less than a bag of sugar, which in my terminology is two pounds [laughs], and I managed to survive. I don't really know how I managed to survive because I'm always grateful of the fact that I did, I'm even more amazed when I knew about Gordon Brown's baby that didn't survive and I did. I know that different disabilities do different things to different people, but I mean that was back in 1947 when things were very different and care was different. I had forceps delivery and my disablement was caused through lack of oxygen or lack of air. But I don't think I was immediately thought of as being disabled, I don't think I was actually diagnosed as having a disability until I couldn't sit up, which meant that I was two before I was diagnosed as having a disability. And my parents didn't receive an awful lot of help either. I mean my father joined Scope [The Spastics Society] Northamptonshire when I went to school and before I went to school, but my actual mother didn't have a lot of help bringing me up or anything like that, it was much more a family thing – the help of my aunts who were older than mother, and my uncle coming in and more on my mother's side than on my father's side...

So were you...

... looking after me.

Sorry. So were you then your parents' first child?

I was. My own situation was such that I was the only child. My father had a shop, my mother didn't work, she looked after me. They bought me a Victorian pram which I could literally lay in. It was flat; it was like a long wide basket on wheels.

And so when you were born then; the fact that you were three months premature, had your mother received any warning that here was the time you were coming to be born?

I don't think so; I don't really know. She never said that, though she said how small I was. I mean she'd got maternity things ready for me, and the hat that they'd knitted me was big enough to cover my whole body virtually, not my head. She said my head was the size of a small orange, and my fingers were like matchsticks.

And so when you were born, weighing as you say the equivalent of a two pound bag of sugar, perhaps less, what was the situation? Did you stay in hospital?

I stayed in hospital until I made five pound five.

Until – sorry?

Until I made five pound in weight or more than five pound in weight. I think I was in hospital until the August, until almost as if I'd been a full term baby. I don't know the exact date that I came home because I think I respect what mother told me and less what mother didn't tell me. I think you have to do that with people cos some things are so upsetting even a long time afterwards.

And incubators; were they around at all?

Something similar, yes. I'm not sure what, but I was put into one. And I'm not sure how often my parents actually got to the hospital to see me cos it's 10 miles from Wellingborough and my father didn't drive because it was so soon after the war, '47 [1947], you know, I'm not sure how they coped with that or anything. I know that the nursing lady used to come in and make sure that I was getting proper nourishment. I also know that I cried a lot, but we don't know whether that was because things were wrong and I couldn't say what was wrong, or what it was. It was never put down to actually anything other than the fact that I cried a lot.

Was that particularly, you know, at first that you cried a lot?

I think it was a way of expressing things. I think it was probably because I have no knowledge of how relaxed I was, because relaxing is something that a person with cerebral palsy has great difficulty in doing. And if you are in pain you tend to go into spasms, which makes things worse. And I've been very lucky, I don't very often go into deep spasm, but if I pull a muscle or anything like that I really know it because it really gives me agony even now.

And so there you were. Then your father worked; what was his work?

He was a gentlemen's hairdresser-cum-tobacconist and it was a one-man business in Wellingborough. And he was also a councillor for a little while on the local council, and then he became involved with Scope Northamptonshire.

Or the Spastics Society as it was at the time...

Which was the Spastics Society then. And he was one of these types of people that saw people's needs immediately because he knew what my needs were. And he was very good about helping people, and my mother was great about helping people. And I think this is where I get my ability these days to sort of deal with committees and things like that, not because they were particularly committee people but because they cared.

You were then obviously, as you say, your parents' first child. How old were your parents when you were born?

Middle thirties; quite old. But you see the war had upset things. I think had it have been possible before dad did military service in the RAF, I might have been born to younger parents. I mean I have no regrets at all because my parents were absolutely first class, wonderful people. And I'm not just saying that in retrospect; they really were first class. I don't think you always appreciate that, but I certainly do.

And where did your father see service?

Well, I went... Ask the question again?

Whereabouts did he serve in the RAF?

He served, he was up in Manchester when the war first started. He didn't fly because he'd got flat feet and they wouldn't have him flying for that reason. I don't fully understand what flat feet have to do with flying; I dare say somebody in the RAF could explain that to me [laughs]. And he helped in the stores and in the end he went to Hong Kong and helped out there in the stores. I don't know an awful lot about it and I feel very sorry that I don't now but, bearing in mind that he died over 22 years ago, he didn't have a very long retirement, so I didn't really have that much time to talk to him, which was a shame. I mean, we did most of our talking at bedtime. He would come, he would tell me a joke rather than tell me a story, which is probably why I've got a bit of a good sense of humour, and get the giggles every so often. [Laughs.] But he didn't tell me an awful lot about his wartime experiences, and mother didn't either. I do know that my mother went to visit dad's people because dad was born in a place called Hilltop which is halfway between Wellingborough and Kettering, and one night there was a blackout and the only way mum could get back to Wellingborough was in a tank. So she had a ride in a tank. I do know that cos she told me that. But I think some people didn't talk about their war experiences because they just didn't want to. And I don't think, I mean my dad wasn't very well towards the end of his life, but he just went to bed one night and failed to get up the next morning. It was quick like that. And I don't think really, because he hadn't had very much retirement, which was a shame, we never really got to talking about things that I think he'd have wanted to tell me.

And so when he was demobbed and returned to civilian life then, did he come back to the type of work he'd done before?

Yes, he'd been an apprentice before cos you were a barber's apprentice in those days; you had to have so many years apprenticeship. And he bought this little business at Midland Road, Wellingborough. And he stayed there until he retired. Lots of people know him, I mean there's still people alive today that knew him, one of my best friends, older of course, but he knew him very well. I mean his love, he liked things

like cricket, he loved going to cricket matches and he was an interesting sort of... He was the sort of person that I am. He used to like going to London and going round museums and doing all the sort of things that improve one's mind. I wouldn't say he was terribly over the top, I mean he wasn't intellectual over the top or anything like that, and he was good fun to be with. And mum, she sort of struggled a lot I think. I think she worried an awful lot about what was going to happen to me. And dad always said that I would survive. Dad was confident that I would see my way through. She wasn't. So consequently as she became older it became a lot more difficult because I was almost her carer as well as she being my carer. The one big thing that she wanted to do before she died was see me settled. Now that doesn't necessarily mean married. She wanted me to go into a home, which I had no intention of doing because I didn't see I could be worth anything in a home. I had had a lot of people get very jealous because of the things that I have done in my life. And it sort of made me aware that, yes, more or less everything that I have has been done with a reason: to help people understand about disability, as well as enjoy myself – I mean I do enjoy myself, so it isn't any strain to do anything like that. But I couldn't do that if I was in a home, I would have to be the same as everybody else. My experience is that people are not always so forthcoming in homes and they do wish that they could do things what they never seem able to do.

And, when you were born, how long had your parents been married at that point?

Well, I think about five years – I'm not too sure on that, but I mean I know when they died they'd had their 40th wedding. When dad died they'd had their 40th wedding anniversary, but as to how many years, it's not something that I really know.

And, your dad back from service with the RAF, your mum homemaker (as it would now be described) – what was your mum's outside work before she became a homemaker, before she married?

She worked as a tailor in a big factory in Wellingborough that employed most of the females of Wellingborough, called the Ideal. And everybody went to the Ideal in those days because it was a place where women could work, because before the war not too many people worked. And it was the beginning of women working, I think. I

mean, when she went there she only had seven and six [seven shillings and sixpence] in wages, you know. During the war she had evacuees because that was one of the conditions because dad was away so the house could cope with more people in it, and she had evacuees from London whom she kept in touch with until the lady that she had died.

These were children were they; young children?

Yeah. I mean I don't remember that because that was finished when I was born, but she did – and she was an ARP [Air Raid Precautions] warden as well during the war; she used to tell me that, you know, she had a certain patch to look after. She particularly remembers the night that Coventry got bombed because everybody could see it in the sky, and that I find incredible.

And I suppose planes coming back or going to raids, German planes, could well bomb around here (Wellingborough) in the process.

Well Wellingborough did escape pretty well. We had about three bombs on Wellingborough; one on a bank holiday, which caused the most destruction, but Wellingborough itself was not hit very much at all. But, I mean, apparently you could still see the lights in the sky when there was a big blaze anywhere, particularly, I mean Coventry's about, oh, 30 to 40 miles away, so you can imagine the destruction.

And when you were born your mum went into the local hospital. What did your parents tell you about the reaction they got, the treatment they got, from doctors after you were born?

Mother never blamed anybody. I mean mother wasn't like that. We had a good family doctor who was my doctor right until he retired, who was also a very good doctor. I don't think they knew an awful lot about disability, but because they were more like country doctors in those days, they did learn more, in some ways they knew more because in some ways they'd seen every conceivable thing happen in every conceivable place – not necessarily a hospital. So in many ways I think doctors were less shock-able and more supportive than they are today.

And in the hospital did your parents say...

I don't know. She didn't talk a lot about the hospital. She never really said. And I presume because I wasn't diagnosed immediately it was just normal, apart from the fact that I was underweight.

And so the diagnosis of cerebral palsy, as it would now be called, where did that come from? The doctors?

Because I was forceps delivery, basically.

Sure, I meant the diagnosis – who did that come from really?

Yeah, yeah. I presume that was what it was because that just happened. I haven't exactly had that said, but I think that's what mother sort of said that, you know, because it was forceps delivery, caesarean, and presumably because it was all happening very quickly [interviewer says something] then it sort of did happen very quickly, if you see what I mean. [Interviewer says something.] She obviously needed to give birth and it just went a bit... I mean I didn't ask because you don't. I respect people's privacy. If they don't tell you anything it's because either they don't think you ought to know, or they don't want you to know, or they don't want to get upset themselves in recalling it. And I think sometimes it's more recalling things that they don't want, that are best left unrecalled.

So you had a caesarean delivery did you?

Yeah.

Which was, I imagine, fairly unusual for that time?

I don't know. I haven't got any idea; I'm not medically, not that medically minded. I certainly don't worry about my disability enough to worry about what happened. What happened happened. You can't take the clock back and you can't say, 'Oh, I must find out, I need to know'. I don't know; there was nobody to ask.

So when you got the diagnosis later, who gave you the diagnosis?

Bonham Carter in London.

Who?

Because I wasn't sitting up and I certainly wasn't behaving as if I was a normal baby.

Bonham Carter – who was he?

A consultant surgeon. Very senior person who obviously had been involved with disability, and quite a well-known surgeon. But I think the fact that he told my mother to forget me, completely shattered my mother. I know she said she cried all the way home and her and dad had a long discussion, but they wouldn't let me go because they love me, and that is unique as far as I'm concerned, absolutely unique. I know people do love, but it must have been a tremendous strain.

So you were being at age two at this time, or approaching two, and his reaction, well, what was the background then to going to London to see this person?

I had a home tutor who was absolutely wonderful. She had been a teacher. I don't know quite how I got her but she was a brilliant lady who I remember very well because she was very good at giving me diction, and she said that I always knew the time because I used to sit and face the clock, and I could tell the time at a younger age than most people. And she used to come in once or twice a week I think, and I didn't have a wheelchair, I had a high chair which was specially made for me by a carpenter, an old family established carpenter's firm in Wellingborough, who made me this high chair, and I used to sit in that. I used to have physiotherapy. I used to have to go every week to Northampton for that, when I was only a certain age. And that was quite horrendous cos that was by ambulance and you never knew what time they were coming and what time you were going to get back and it really messed the days up for mother because father was doing the shop, mother used to have to take me, and it was

I think quite dramatic because the ambulances in those days were all dark glass and it was a bit sort of hairy to say the least.

This was later on when you were a toddler, was it?

Well, I think it was probably really between the years of five and seven.

And so when you were two then and you went to London, what was the trigger? Why did you go to London?

I don't really know the answers to that. I remember having my own tutor. The next thing I remember is going to the hospital place and coming home at weekends.

That was later on. We'll perhaps discuss that later on, Dorcas. But the advice of this surgeon to forget you; what was he then proposing? How was it that you...

Put me away I would imagine. That's the only interpretation I can make of it. Put me away, forget you've ever had this child, she'll never be any good, that sort of thing. And it did colour mum's and dad's judgment for a long time because they never had any more children. They applied to adopt and the sad thing was about that - I was at school at the time - they applied to adopt but the adoption society said yes to mum, yes to dad, but when they knew I was disabled they turned it round and said no. And that was the biggest single grief I have ever had about being disabled. Because it would have given mother so much of an easier time, and my father, if there'd have been somebody else. And I don't think I would have got spoiled any more than anybody else, I think we would both have been treated equally. And I still find that a very hard judgemental statement, you know, just because I'm disabled another person might not fit into the family. That is what makes people disabled.

And you were living just outside Wellingborough. In terms of family support, members of the wider family, were there members of your mother's and father's families around at all?

Mother's family were superb. I mean I remember going to all of their houses, practically. Father's family I didn't know. I never knew any grandparents because they died before I was born. I've heard a lot about my mother's mother and how hard she had to work and about her, but I never heard much about my father's family. Father's family were around but I didn't see them and when the children died – one died in a motorbike accident and one died quite young - you know, I didn't have the continuity with them that I had with my mother's family.

And they had lived in the area as well had they? Both...

Oh yeah. It's a very localised family, really. There were the daughters and sons of them (mums' brothers and sisters) tended to move out, but mum's actual brothers and sisters actually lived in this area.

And were you ever made aware of what their reaction was to your arrival?

No, they were very loving. Probably over loving if anything. It sounds a weird thing to say but they probably spoilt me.

And I suppose you referred to... Sorry Dorcas, we're just about...

[End of Track 1]

Tape 1 Side B [Track 2]

OK. You referred earlier to your parents joining the Spastics' Society locally – as it then was, early times, 1947 when you were born – you'd had the visit to London, the advice from this particular doctor. In those early years as a toddler, two, three, four, five; what choices were made available to your parents? What options were they given?

Only where I went to school, nothing else. Mother still had to do everything for me; I mean she wasn't offered any help on that sort of score. And I think they just coped because it was either cope or don't cope. And they didn't want to not cope, they weren't those sort of people; they coped.

And when were you first able to walk?

I've never walked. Well, I say I've never. I have worn callipers which we were all forced into. And really I think a lot of the modern damage that I'm suffering now with bones and things is because we were forced into them, because they were waist callipers which meant they had to go round our waist, they were hinged at the hip and hinged at the knee. They were heavy and although it meant I could stand, it didn't do much else, and it certainly didn't do my back any good whatsoever because bones – when you are young – are forming, and callipers were harder than bones at that time, and I'm sure this is why some of us have got the problems that we've got. My friend in London who's also got cerebral palsy, she says exactly the same. You know, because of the way we were, we wore the callipers and that they were standard sort of issue, you know, we were just put in them and that was it.

And you referred earlier to having physiotherapy locally. How frequently was that?

Quite frequent at St Margaret's, but very infrequent at De la Rue [School].

This was when you were at school. But before you went to school, you know, aged two, three, four...

Yeah, before I went to school it was like twice a week I would think. I would think, I can't exactly go back that far. But I would think it was twice a week.

And so do you remember what the main sort of idea behind the physiotherapy then was, before you went to school?

Yeah, to make you relax, because you're not always relaxed when you've got cerebral palsy, and...

So, when you were around two and three and four and so on before you went to school, you reckon physiotherapy (taken by ambulance) a couple of times a week. Do you have any memories of that early physiotherapy?

Yes, I remember holidays. Because my dad was six foot tall and he could have me in his lap and I could dig in sand and I could sit in water if he sat behind me and held me up, so I had lovely seaside holidays with my auntie and uncle who used to take us.

That would be around then this time it would...

Yes.

What is your earliest memory then, Dorcas?

When we went to the seaside to Devon and Cornwall and some of the places we went to on the east coast. More further away though because the east coast is notoriously cold. I remember the coronation because that was quite a vivid day. It was one of my early memories because we got television for it and funny little televisions they were, not a bit like televisions today, and everybody came to see the television; it was wonderful! I think my mum, the whole of that day (other than when mum was doing things like taking me to the toilet and things like that) she made loads and loads of sandwiches and loads and loads of pots of tea so that anybody who came in got a sandwich, a cake or a bit of, or a cup of tea or coffee, cos they all wanted to see the queen, they all wanted to see TV as well because TV wasn't a big thing in those days, and not many people had them.

And so it's fairly unusual to have a television?

Yeah, yeah.

And how old would you be then...

Five.

... in the year - ?

Five, just about five, probably just under five actually. No, just over five, that's it.

And so can you remember, can you describe the television to me?

I remember they bought me a little chair, a little easy chair like what you get for small children these days. Now I don't know whether they bought it or had it made but it was a super little chair and I remember sitting in it, it was very comfortable; it sort of fitted my body. I could sit up anyway, I was quite capable of sitting up. And I used to love being in our back garden with a cricket bat and somebody would roll a ball along the floor and I'd try and hit it. And I remember pushing a dolly pram from this little chair, you know, just backwards and forwards. I didn't know that many young people at all.

So you'd be sort of five and around that time when you had this chair?

Yeah. I mean I don't think I knew many able-bodied children, and I certainly didn't know many disabled children. I mean, my dad knew more because of his involvement with Scope (the Spastics' Society). He knew a lot of people who were about my sort of age.

So what was your father's involvement then when you were this sort of age, five and so, with the Spastics' Society?

He was a committee member. I think he was Treasurer for a little while, but he also used to do the round of visits, to visit new people and to assess their needs, because a lot of the assessing was done locally.

So, in that way then, he was quite involved in the local Spastics' Society, as it then was.

Yeah.

Even, as you say, to the extent of helping to assess other children. Did he ever talk to you then about his feelings about that involvement, about your arrival and...

Yes. I don't think he ever thought it would ever happen that he would have somebody disabled. But I also don't think that he certainly didn't think of me as a lost cause, he thought I had lots of things going for me, which was great because I think you need that, you need to know that people are with you. I think one of the difficulties is if you think people are against you, then it's not very easy for you to cope.

And just to go back to the coronation; there you were watching the coronation, neighbours, friends gathered round. Your parents then knew quite a lot of people did they, round and about?

I knew quite a lot of older people, quite a lot of dad's and mum's friends I knew because they would come in and they would see, and I certainly knew mum's family very well. They used to come on a Saturday night and play cards. Those that didn't want to play cards used to watch the television, and the rest of them used to play cards and have sandwiches. So it was like a regular Sunday night get-together, which carried on for a number of years until people either died or didn't want to do it any more. And I suppose family life was like that then.

So it would be a mixture of family and friends would it?

Oh yeah. More family on the Sunday night, but I mean dad was never ashamed to tell anybody about me. And he used to talk about me quite openly to people as he cut their

hair, because he had a photo of me in the hairdressers and people used to say, 'Who's that?' and he used to say, 'It's Dorcas.' And, you know, I think quite a lot of people knew mum and dad so they knew me. Whether they understood me, or whether they understood what disability was about, I have no idea, but certainly my father was able to talk about me; I wasn't hidden away at all, there weren't the options that there are today. I mean, I must have had a very tame childhood, but it was a childhood that was a good, for me it was good. I have no complaints about it. I don't wish that I'd have done anything different.

And just to return to sort of family history, the choice of your name, Dorcas; where did that come from?

That was my grandma's name. I'm named after both my grandmas. Elizabeth was my dad's mum and Dorcas was my mum's mum. And they decided to call me after my grand... I mean, I think my mum's mum must have been a lovely lady. My dad's mum was deaf, Elizabeth was deaf, and I don't know much about her really.

So given the fact that your dad's mother was deaf, do you think that had an impact on your dad's attitudes?

I think it must have done although he didn't really talk a lot about it. Bearing in mind that being... Dad's was a one-man business, he was out at nine in the morning and back about eight at night. I know he came home for an hour at dinnertime, but there wasn't the type of conversation, and what happened he'd work all day Saturday so virtually the only time he was around was Thursday afternoon and if there was cricket on he'd go to a cricket match or to meetings or whatever, and Sunday. So I mean, and he used to like laying in on Sundays because it was the only full day off he had.

Thursday afternoon being half day closing?

Half-day closing, yeah.

And do you remember much being described to you about, you know, his decision to buy the shop and to run his own business?

He rented the shop, he never actually bought the shop, it was rented. And by the time he retired, which was about three years before he died, three or four – he didn't have a long retirement – he wasn't very well anyway and the supermarkets had started flourishing and really it was hard work because he could never sell anything as cheap as the supermarkets could, and small shops were going out of fashion like there was no tomorrow – unless you happened to have a grocery shop, and dad's was just a tobacconist/gentlemen's hairdressers with toiletries, which are not the most sellable of items. And although he had the people that came in for their haircuts that would buy things, he also knew that they could buy things cheaper in some of the supermarkets.

We talked earlier a little bit about, you know, your early memories of your holidays. When you went on holiday, how long would that be for?

One week. It was as much as dad could do, one week. But occasionally we'd go out in between; my auntie and uncle on my mum's side could take us because dad didn't drive and he didn't want to drive. He didn't need to drive cos we'd always lived near to the shop, we'd always lived in Midland Road, you know, and he didn't feel the need to drive so he never drove.

And so when you went on holiday to either the east coast or to elsewhere, how did you get there?

They'd drive us; auntie and uncle. We'd go with a sort of 'five-some'. Which was quite good in a way because it meant that mum had a bit of a help. So we all had rest because my dad used to insist that we had a proper holiday where meals were provided. In other words we didn't have to cook our own meals so it was a real holiday, because he needed a real holiday, my mum needed a real holiday, my aunt and uncle were able to go with us because they'd got a slightly better income than we had, and so it was a... And my uncle was also a hairdresser in Kettering, and it just suited... My other aunt and uncle, they used to take us sometimes and it was the same with them. When they went on holiday they only went for a week and it was literally one week a year.

And what kind of car, typically, did you travel in?

Well, in the summer when it was nice weather, and sometimes it wasn't nice weather, [laughs] but we'd go there in my auntie's car or my uncle's car and we possibly would use the car but possibly not use the car...

So what sort -

... cos we were very particular where we went.

What sort of models of cars did they have?

One uncle had an Austin Seven – a very small one that was a bit bigger towards the end. That was a bit of a squash, you know, getting five of us in. But my other uncle had a Wolsey. It was a very old Wolsey but it was a lovely car; big, plenty of room, the seats were low, sort of lower and the dashboard was sort of wood. I'm sure they had other cars but I don't remember what they were.

Just trying to get a picture of, you know, the sort of scene really. And did you then, what, stay in small hotels?

Yeah, we'd stay in small hotels. Generally mum and dad would have a family room because up until I was a teenager I was still small. You know, I mean, mum and dad could look after me if I wanted anything in the night. But actually, because we were at the seaside with the fresh air, I just used to sleep. Even if it was a strange bed I still managed to sleep because the fresh air did me so much good. And, you know, we'd only go down to the beach and I'd play and sit in the water and mess around, or some... I mean that was more when I was younger we did that. As I got older we sort of got a bit more adventurous and went to places. You know, other than where we were, where we were staying. But when I was very small it was mostly one place; go to one place stay at one place sort of thing – stay and stay on the beach, and do the sort of normal holiday things.

And did... [Bell rings and interrupts.]

Oh Gawd.

[End of Track 2]

Tape 2 Side A [Track 3]

Thought we'd start talking today, Dorcas, about your education, which we've touched on in the previous tape. At first then, you had a home tutor, did you?

Yeah. She was a lovely lady. She was a near neighbour anyway. She'd been a teacher; I mean, not as a teacher would be today because she must have been one of the very first few female teachers there were. She taught in a school. I don't know a lot about her background. She married a local musician who kept a record shop when records were just coming in. You know, you're talking about late fifties, early sixties. He was also a talented musician who could play organ, he had a baby grand. He used to play in their flat which was above the shop, and if he opened his back window we could hear what he was playing from where I lived. And that gave me an insight into music. But she was a very patient lady; she'd got plenty of finesse and she wasn't always ramming it down you, she took it calmly. And I suppose really I owe her a great deal because I think she must have taught me a lot more than I realised at the time. And I can't really remember what her lessons comprised of, which is a pity, I would like to, but I think because she came to me it's all sort of gone blurred in the background.

And so what was the decision that led to her coming in the first place?

Well I think because I should have been at school; I wasn't. I don't think they knew quite what to do with me because there weren't that many disabled people. I mean, I had a friend, or mum and dad had a friend who was disabled with cerebral palsy, who's that much older than me (who's died, incidentally, quite a number of years ago), but he could walk. And of course his main problem was because he could walk and because of the way he walked, he got called everything under the sun, because people used to think he was drunk. Well he wasn't at all and, you know, we were all a bit familiar with that, even how horrible people complained. I didn't experience the same kind of thing at all. I think it was because I didn't know many able-bodied people when I was younger. I knew the family, the family knew me, I didn't know many people of my own age group at all.

So your parents knew of this chap; he was then a boy, was he, when -

Yeah. He lived in Wellingborough and I would say he was 10 to 15 years older than me.

And so your parents knew him did they, you know, before you were born?

Yes. I think somebody used to take him to dad's to have his hair cut. Quite a lot of people with disabilities – not necessarily cerebral palsy but other disabilities – used to go to dad's to get their hair cut. I think it was because they identified that he could cope and not get in a panic about it, whereas, you know, or perhaps their parents went, you know, their dads. But, I mean, dad had more than one disabled person go. I don't think he had people in wheelchairs because well there weren't wheelchairs, wheelchairs as we know them today. There wasn't that kind of conveyance. I mean I had a long Victorian pram and even when I went to school I don't think I had a proper wheelchair, you know, not what you could definitely say to somebody, 'Oh that's a wheelchair'. I certainly had a wheelchair by the time I got to my second school, but, again I didn't sit in it all the time because they had wooden chairs which had two castor wheels on the back which they could tip up and trundle along from place to place. You didn't actually work them, the staff moved them. They had various straps on to keep you in the chair, but that's a later story.

So were you ever told, you know, in regard to the home tutoring, did your mum and dad then talk to the local education authority?

I would think so, I would think they talked – I didn't know much about it, I didn't know what they talked about. But I went to John Greenwood Shipman Home which was run by nurses from Mansfield Hospital who did night duty and looked after us physically. We used to have to get up at six, or even earlier, because it was like a strict hospital routine: you got up early, you went to bed early. But you actually had teachers teach you in the daytime. And one of the odd things that I remember, other than being taught, I remember it was a big old house, which is hardly surprising – it would probably have had servants when it was used as an ordinary house – it had had extensions put on; the bedroom was on the ground floor of a new extension at the back, there wasn't very much garden but I remember being able to use a tricycle at the time and going round this little plot of garden which was very small because they'd

built up most of the other area with the extension. The actual teaching part of the school was in the old part. Although it was flat to get in and one could move about when one was in there, access would leave a lot to be desired. The toilet was very small and I really don't know how they managed us in [a] such confined toilet really.

So this was after a couple of years of home tutoring. What was the name of your home tutor?

My home tutor was called Gertie Jordan. She had taught at All Saints, which is just across the road from where I live now, here, and I think she'd taught at one other place. She wasn't retired, I mean this was before she retired obviously, but she had had experience behind her. I don't know how we come to get her. Whether the education authorities looked for somebody and found her, or whether she knew that I was disabled and felt that she could do it, I just don't know. I never questioned that. You think about these questions afterwards and wish you'd have asked them. But it's awfully difficult cos sometimes people remember things and sometimes they don't.

So you had Gertie then at home as a home tutor, what, for a couple of years was it?

Yeah.

And then came the decision to join this other school. Where was that, in fact?

In Northampton. And we stayed there from Monday to Friday, and came home at weekends, generally either by private car services which mum would come over in the car, not in our car but in this private car, and pick me up, or by the ambulance service. And it was very, very emotionally unsteady for me actually, if I may say so. I wouldn't be scared of it now but it tore me apart when I was that age because it was a completely strange environment for a start, and keep coming home for weekends I really didn't want to go back on the Monday. And, you know, because it was just weekends only I still didn't get to know anybody other than the people that were at school, and other than the people that came to see me, which were the same people that had always come to see me – family basically. And because my life had always been family orientated, I had no concept of what it was like to have friends of my

own. I mean, yeah, I had friends at school, but they all disappeared on a Friday and then I saw them back on a Monday, but we didn't really have... Because it was a hospital school, because we were up so early in the morning, we also went to bed about three hours after school finished, so we had quite a lot of bed time and not a lot of actual conversation time.

So in terms of numbers then, and indeed ages, what sort of numbers of children were there?

Fifteen, 20, not more. I mean some of the more local ones came in, in the day. I don't remember to be quite honest cos I was there just over a year or less, if you see what I mean, and I don't think I really took an awful lot of notice.

So it was attached then was it, to a hospital?

It was attached to a hospital. We didn't go to hospital; they just lent us their staff to cope with us, if you see what I mean. And to just make sure we had some sort of education. I mean, I can't really... We had physio, I do remember that; I don't know whether they had a speech therapist and I can't remember whether they had an occupational therapist or not. Probably not. Probably only just because the hospital also had an area which used to be what they call open air for people that had had TB [tuberculosis] and suffered gas or things from the war. And the hospital also had a sort of place for that as well. We didn't go there but there they did physiotherapy as well, and they certainly did physiotherapy with us, but that's about all I can remember.

And so around 15 or so children. What kind of range of disabilities or conditions did the children have?

Well most of the people that I associated with had cerebral palsy. I think it was basically for people with cerebral palsy. But I think there was a... The friends that I've still go now, that I still know about now from those days, were about as disabled as myself; perhaps a little more, perhaps a little less. So there were quite a number of wheelchairs, I do remember that. But there was also people that could walk and get

around. And I think it was a very good starter from a learning point of view, but it wasn't long enough to imprint itself on my mind.

And it was the John Gorman School. That was the name, wasn't it?

John Greenwood.

Green - Sorry, John Greenwood School. So at the John Greenwood School, Dorcas, of the 15 or so children there, what sort of age range were the children?

Difficult to say really. I would think from about six to about 12, possibly older, but I don't really remember. And because I was only there a year I can't say that many people came or left during that time, if you see what I mean. I wasn't there really long enough for me to be able to guess what sort of ages they were.

And the National Health Service was just beginning, or had just begun, and do you know then whether the hospital, the school, that was run was it locally?

It was a local thing certainly. It was certainly local. I don't know whether the house had been given. I personally think it might have been because all the big houses up there, and they're still standing, and it's used now for training for disabled people, work training and that sort of thing. Because, obviously it was only very small but it was still something where some people could go and where there was enough room for A: an extension which was a dormitory which had about eight or nine bedrooms, and B: I would think it was possibly given or made available to the county council who made it available to the hospital, or even given to the hospital for them to use for something.

Then you had, what, two dormitories, did you? A 'Boys' and 'Girls'?

Well, yeah. One of the things I do remember, which haunts me to this day, [laughs] is there were certain things we had to do. And one of the things we had to do was drink hot milk before we went to bed. I can still smell this blooming hot milk. Oh, it wasn't so much the hot milk; it was the smell of it. They'd get it all ready for us and the

smell was overpowering, you know, and make us drink it, and sometimes it would have a skin on it, which completely used to put me right off. I mean I can drink hot milk in coffee fine, as long as I don't get a whiff of the hot milk. If I get a whiff of the hot milk, I start thinking, oh dear. It's funny how you remember things like that. I mean the rest of the food must have been good because I don't remember thinking, 'Ooh, I don't like it'. The thing that I really found a bit tiring was they'd wake us up so early then they'd bring the bed pans out then you'd go on the bed pan or whatever, then you could go to sleep for an hour like you do in hospital, and then they'd wake you up again. And I found that odd. I thought they could have got us up because that hour was a completely wasted hour. It was an hour where nothing happened yet you were awake, because you'd been woken up. You know, that always seemed to me a bit sort of stupid to me, because OK there was never enough nurses to get us all up at once, and of course you did have to wait your turn like you always do have to wait your turn. I didn't mind waiting my turn but I did find the hour a bit irksome.

And you had the two dormitories, you know, the particular routine of the hospital getting up early. Where then did you eat?

We ate in a dining room but I couldn't tell you anything about it. I think there were round tables and I think there was always enough staff on to feed us, even if one staff sat between two of us and gave one a mouthful then the other a mouthful. They didn't eat with us but then none of the school that I went to did the staff eat with you; you always ate before they had theirs or after they had theirs.

So how were the lessons organised?

Well the lessons were about the same. You know, nine till 12, something like that. We had cold milk; I think they were very good at giving us things that would help our bones and things like that. They seem to have been very good about the food and everything. You know we weren't lacking in that respect. I just don't remember what we had but I remember that I ate it, and I mean whereas at my other schools I remember more of the food, and in some of them, particularly in the last school that I went to, the food in some cases was awful.

So the lessons were given by what, one particular teacher or - ?

One or two teachers, yeah. Afternoon; we always finished at four, but then we were in bed by about seven to half past, you know, and I think these are the times when – apart from, we'd had supper or tea or whatever you call it in between then – we'd had time to go out and walk in the little bit of garden or do what we wanted to do. I don't remember very much about what we did. I know when I tried to pull a dolly I enjoyed that. I think we must have had physio in that time as well because I don't think we actually had it in school time.

Yeah. And of course the arrangement of going to bed 7:30, different experience in the summer from the winter, days perhaps before central heating, as well. How did you feel about being away – although not that far away – but away from your parents, then?

That was horrible. I didn't enjoy that a bit. I enjoyed learning because I've always enjoyed learning, and I can see a positive thing in learning. But, like all places, and it certainly applied to all three schools, possibly not quite so much at St Margaret but it certainly applied to the last one; when you're away and you're growing up, coping with having a disability and not being able to do certain things and not being able to meet able-bodied people and having all these rules forced down your throat about you're never going to work, you're always going to have to rely on people, you're never going to have a boyfriend, you don't fit in to convention and that sort of thing, it's awfully difficult to find somebody who you can have a conversation with who understands what you're going through. And I don't think anybody did. I mean they were very good at our welfare – and by welfare I mean our physical being that was looked after – they were fine with the physical being, but not the emotional being at all. And although one grows, one also learns to be a bit like Tom Brown's Schooldays; one has to make decisions, one has to say well what am I going to do about it? Nothing, or what? And so I've always been able to make decisions and I think that's why. You know, I don't dither; well I try very hard not to dither because dithering doesn't get you anywhere. Sometimes you can't make decisions and decisions are certainly harder to make when you're younger than when you're older.

What are your memories, Dorcas, of, let's say, the first day or indeed the first week at the hospital school?

Repeat that again for me?

Sorry. What are your memories of the first day or perhaps the first week at the hospital school?

Intense loneliness at odd points. You know, loneliness can catch you out even when you're busy sometimes, you just suddenly feel lonely. I mean, can you stop a minute, my knee... [Break in recording?] But it was a sense of adventure as well, and I like senses of adventure, I like doing things that are different, and it got me out. I don't think I appreciated the rides backwards and forwards in the ambulance and things like that, but I did appreciate the car drivers because the car drivers were registered car drivers and they were very friendly, even if I could not answer them, and even if mum did some of the talking, you know. I think that was important as well because mum didn't meet many people, looking after me, and I think it gave her somebody else to talk to as well. So yeah, I think it was both. When I was working, when I was actually enjoying what I was learning, it was fine. It was just when I went home and had to go back again.

And the age of the possibly donated building – what age was the building itself?

Georgian, Victorian. Very stolid, very stolidly built. A big building, you know, possibly three floors. I mean two big floors and possibly attics. The sort of houses that you see that were built over about a century or more ago, probably more, very solid. I mean a nice house and I think probably the additions to it spoilt it, because the additions were very modern. Well, not very modern now but very modern when they were put up. I mean, they were just like temporaries almost. They were a bit more than temporary but they looked added on. They didn't match the rest of the building at all. [Laughs.]

And as you remember it, Dorcas, how would you describe the atmosphere of the school?

The atmosphere was OK. Not as good as some places I've been to, but a lot better than other places. Atmosphere is what you make it. I mean, sometimes it used to be great and other times it didn't. You talking about central heating reminded me of something; I actually got my hand stuck behind a central heating radiator, and I got burnt. And that was I think possibly due to the fact that it was a long... As I said, the toilet that we used was in the old bit of the building when we were in class, and it was just one of those things. Nobody said anything, nobody got upset about it; it was just one of those things. But, you know, I'm always wary about where radiators are to where people are and how you can alter a room to make sure that at least you're not going to stick your hand on a radiator or you're not going to put your hands down a radiator, or the turning moves more and all that sort of... But that has only come more recently, and they just had to make do with what they'd got, which is what they did.

And can you remember your feelings perhaps at the end of a day, trying to get to sleep, maybe it was light outside, this kind of thing?

I never find it easy to go to sleep when it's light outside. I never have. I mean, all during my school life bed times didn't alter that much. I mean, OK it was about seven to half past at the first school, it was about half past seven at the second school, and the last school I went to it could be as late as nine because we did prep at that school. But it was still light when you went to bed, and that I found really difficult. I don't find it difficult when it's dark because I think I can go to sleep quicker and also everybody is a lot quieter when it's dark, everything settles down quicker. And that applies to all three schools, you know.

And so you were there just for the year. What were the decisions then that were open to your parents and to you in the run up to the end of that year and then the choice of the next school?

I don't really know who made the decisions. I think the county council possibly made the decisions in conjunction with my parents, and I went to St Margaret's School, Croydon, Surrey, which again was a big house given to what was then the Spastic's Society by a Miss Jean Garwood, who I remember. She'd given the house...

[End of Track 3]

Tape 2 Side B [Track 4]

She'd given the house to be used by the Spastics' Society, as it was then. And she was a 'lady', that's all I can really say. I mean, I spoke to her and said hello to her and things like that, she did live nearby so we did see her occasionally. The nicest thing about changing of schools were because it was bigger and because it was... The Spastics' Society and Scope had got their heads together, and Alex Moira and one or two disabled people that had played a big part in getting Scope (the Spastics' Society) off the ground, were there to advise because they'd got disabled children themselves. And although Alice Moira never went to that school she did go to Thomas Delarue [School] when I was there, she was older than myself, and her father played a big role in getting Scope off the ground – in getting the Spastics' Society off the ground I should say,

This is Alex Moira...

... and, you know, there were lots of people at that level involved; I mean it was a headquarters level thing. The teaching staff were absolutely excellent, they were 'A1'. They taught us everything, well more or less everything. And everything was good. It was a real adventure into learning. They taught, they did things with us, so that they made sure we learnt without hassle. I mean they did things like painting for those that were on limited mobility. They did nature study lessons when you got things, we had communication with a butterfly farmer who'd send us caterpillars that turned into butterflies, stick insects; they'd have musical events for us, you know, they'd make sure we had a good grounding in art and music, history, geography, and they had to plan it all. I mean we only had one teacher for the class and rather than move up or down, like you do in... we had more or less the same teacher the whole of the time.

So what we should remember, I suppose, is that here we are at St Margaret's in Croydon and it was a relatively rural setting.

Yeah, and it was absolutely superb because she'd got fully mature trees in the garden, we could go out into the garden, those that could push themselves could go and wander round the garden, and the garden was big enough to wander round. I mean it

was quite a large garden, very large by today's standard. It had mature trees in it, it had lovely rhododendrons bushes; a lovely garden. More like a garden of a country house than a garden of... well it was a country house. And it was just like it was a very, very Constable place. Again it had had lots of things added on to it, which weren't so good, but it didn't look so odd as John Greenwood because it wasn't so tacked on. It was more carefully thought about, and so the main frontage of the house was as you would see a house basically. And also a great thing was we actually were allowed guides and scouts, not to come to us but to start. I had a guide group, a brownie group, a scout group, a cub group, all run by local people, they used to come to us, which was wonderful because here were real people who lived in the real world out there who taught us things about the real world, but not only taught us about the real world, occasionally the real world came to us. And so we weren't quite so cut off.

And so when you were at St Margaret's, the mid fifties this would be then, the mid to late fifties? What sort of numbers of pupils were there at that time?

I would think there was – I've been trying to think of numbers – and I would think there was about 50 or 60, between 50 and 60 of us. Ebbled and flowed. And I can't remember much about the bedrooms. I can remember a lot more about the enjoyment times that we had and the fact that the staff worked so very hard to involve us, you know, so we weren't just sat there listening to a lesson, trying to remember it from speech to speech, if you see what I mean. We were actually physically encouraged to do things to help us remember. So it wasn't just somebody talking 20 minutes and not doing anything.

So the teacher would be standing up and coming round to you, and how...

Standing up and moving around.

How would they... What kind of teaching methods would they use in particular?

Mainly verbal because there wasn't any other way. I mean there wasn't any adding machines, any calculators or anything like that, everything you had to do how you did it. I don't remember how I did, I mean, I must have written things down or somebody

must have written things down for [me]. I have a far more vivid memory of things like art and music and drama and painting and history of art and all the things that we could visibly do – in other words things that we could visibly do and things that we could do to produce something – than I have remembrances of maths. And this cold feedback, cold talking. We didn't have typewriters; they didn't come in till I went to Delarue. Because the garden was so large and comfortable we were able to go out. And next door was, well, not very far away, was Coombe Farm, which was a residential centre for older people who'd left school, and occasionally they used to come through our grounds. But I mean the guiding and the scouting and the cubs and brownies was superb because they got us to do things we'd never done before. I mean they'd take us out and show us how to cook sausages, and although we weren't supposed to cook sausages ourselves they'd hold our hands and help us to do that and it was great cos it gives people a sense of 'Yes, we can do it,' rather than, 'oh, you can't do that, you're disabled,' which was, I mean, that's around now but it was around a lot more then.

And at St Margaret's, you went there after a year at the hospital school, you were in Croydon, and so you stayed there, did you, for the whole term?

Yes. Perhaps we went out one weekend. Our parents were allowed to come and collect us; my parents usually came down once a term. If it wasn't dad, it was mum and auntie. We didn't go out of school very much because taking that amount of people would have been a major overhaul, and I don't think they were into that in them days. We did have plenty of visitors; people who were interested in seeing how the school worked and things like that. These were always shown round by the headmistress, who was very autocratic. What she said, went. My teacher was just wonderful. I mean, she'd tell us about where she'd been on holiday, and she'd make the place live cos she took slides and told us and showed us photos, and she went to Assisi in Italy and she brought the most wonderful slides back. Well I've been to Italy you see,

What was -

and it was exactly as I remembered her saying about it. And that was special.

What was her name Dorcas, your teacher?

She was named Miss Evans.

So Miss Evans then was teaching sort of how many of you?

Twelve, about 12, anything from 10 to 12 of us. Never more than that though because we'd each have our own desk, and the chairs as I said were wooden and we sat in them and they'd tip them up on their back wheels and trundled us along. We did have wheelchairs but only a little bit and we certainly... well if we wanted to go out in the garden we'd probably have wheelchairs, those that could manage it; those that couldn't manage, they stayed in their little wooden trolley things. We had speech therapy, we had occupational therapy, and we had physiotherapy. Probably physiotherapy twice a week, occupational therapy once a week (maybe twice), and speech therapy if you needed it, [inaud]. Speech therapy has always seemed to be a bit of a problem to get the speech therapist. You know, it had to be shared out among so many people because, again, quite a lot of people had speech problems. [There were] those that didn't need the speech therapist, and that was why there was probably only one speech therapist. Whereas there might have been two OTs [Occupational Therapists] and there might have been three or four physios.

And with the OT, the occupational therapy, what was the sort of things you did there with that?

Teaching us, because we were in callipers you see, teaching us to... we had one thing that they don't have these days, for which I was quite thankful...

I just need to adjust your mic a bit.

Oh dear, sorry about that. And that was bed rest hour. We used to have to lie on our beds and not move. Which was a bit of a pain in some ways, but it wasn't in other ways. That was supposed to give you time to relax.

That was, what, after lunch was it?

After lunch, yeah. Then we'd go back in the afternoon, do the afternoon school, finish, somehow we managed to finish roughly about the same time as school finished even though we'd had the hour's break sort of thing. We had weekends to ourselves but they weren't television orientated, they were weekends where you played with things, whatever you could play with. I remember playing with a panda; wasn't my panda they'd just got so many things given to them that you didn't need to take any toys – all you needed was pocket money and sweets cos the sweets were for yourself but you could share them with others because, like everything else, some people had lots of things and some people had nothing. And these were kept in a tin with your name on.

So where did you buy the sweets then?

They were sent to us, you know, by family or what have you. We didn't actually buy anything at that school, there was no... We had money paid out to us, like money for guiding cos brownies and guides cost about two p [two pence] at the time I think for weekly subs. And you'd need money for church because that was one thing that was insisted on, that you went to church. Which was quite good in way cos it took up the whole of Sunday morning to get people to church. Not everybody went I don't think; I can't remember. But I think there was more interest at that age. When I say interest I mean people actually coming to us. I think it was possibly because we were little less concerned about achieving academic glory if you like [laughs]. No I don't mean glory but something similar, you know, achieving academic fame. It was just more or less to give us good grounding and it did give us good grounding cos I think we did much more easily because the teachers were so good.

And at weekends, the teaching staff were they still around?

Yeah I think they were, yeah. Miss Jill Walker is certainly. I mean they must be getting on in their eighties.

No, sorry I meant did they stay, you know, at St Margaret's with you? Where did the teachers live then? Did they live at St Margaret's?

No, I think they came in. I don't quite know where they lived to be quite honest; ours was not to reason why, you know. Some of the house mothers lived in that looked after us, cos we weren't looked after by nurses, which was quite a relief. And they'd got a system where they could get us up and put us to bed pretty quick. Quicker because some of them had been doing it years. And that was even with callipers, you know. And Miss Bird – that was the headmistress – she ran a very tight ship, you know, and there was always somebody on every night so you were never left. If you had an emergency you'd get somebody. And really it was very pleasant. Again I found it an awful strain going back. But once I'd got into the routine I enjoyed it.

And you referred earlier to particularly occupational therapy and the fact that you were wearing callipers. So were a lot of you wearing callipers then at the time?

Awful lot of us, nearly all of us. I really do think it was a trend, I don't really think it benefited a lot of people. It was just that they thought it would strengthen us and make us relax and make our legs go straight whereas our legs wouldn't go straight even with callipers, which again, as I explained yesterday, in the bone situation is not very good, because when your bones are growing they don't want to be manipulated in the way that sometimes callipers can make you. Because callipers are hard and your bones are soft and I really do think there is a slight danger there.

So what kind of callipers were you wearing yourself, Dorcas?

Pardon?

What kind of callipers were you wearing yourself?

Ones that came round the waist. That were horrible cos occasionally they pinched you cos they had a long metal shaft that was a bendable a bit of metal that slid in, one bit into the other, so that they were right the way round your waist like trousers are, tight. They had a joint at the hip which meant that you could sit up and lay down, the joint

would move, and a joint at the knee which mean that you could bend your leg, but they also had a locking mechanism which, when we were in the bed and rest hour, we had to sit with the locking mechanism on and the legs sticking out in front of us. I mean I think it was so early and everything was in so much of a pioneer stage that somewhere somebody had thought these things were a good idea. And for some disabilities they were because for some people they could actually walk with them whereas they couldn't walk without them. But for people like myself who didn't walk on them, they were a bit of a nightmare to be quite honest, you know, you had to be so careful because they stuck in you in so many places and made you sore. I remember my knees used to suffer where they bent because the strap used to rub at the back of my knee where the guide – the pinion thing – came at the back. And very often people used to have open sores there because the strap would rub or they'd somehow get caught up with the locking mechanism and they'd have lumps out of their knees and things like that. Not very often because the staff were adept at putting them on, but they weren't easy things to put in and of course they weighed half a stone or a stone in weight. I mean, when I came home mum and dad never used to put them on cos really it used to kill mum to put them on. It's all right when you're used to doing it, but when you're not so used to doing it A: it's hard work on the person putting them on, and B: it's not fair on that person who has to struggle.

So you were wearing them, you were asked to wear them for, what, all the time that you were at St Margaret's was it, including weekends, all the day?

Yeah, yeah, virtually. And we came home for holidays and my parents and that they came up to see me once a term, and that's really all I can tell you about it. I did enjoy being a brownie and I really did enjoy being a guide. I am always eternally grateful to the scout and guide movement who always accepted people with disabilities without any question at all.

So just to return to the callipers then, Dorcas: at night, what happened then?

At night I think we had a small prep but not very long. We weren't in bed much later than what I was, I should think possibly when I got there it was half an hour later so it

was half past seven instead of seven, then it probably got to about eight by the time I left, and then I went to Delarue.

So with callipers though, you weren't asked to wear them in bed were you?

No, they took them on; I mean they took them off. And bedtime was staggered somewhat and again we always had a cup of drink and a bit of toast before we went to bed. We had breakfast and we had dinner. That food seemed to be quite reasonable; I don't remember thinking that I didn't like anything. I expect I did at the time but if I did I don't remember it.

But no hot milk this time?

Oh, apart from hot milk, yeah! [Laughs.]

And so you went to St Margaret's then at, what, sort of eight-ish I suppose you'd be, would you?

I was about seven and three quarters when I went there, or seven and a half, and I left there when I was 12. Either 11 and a half or 12, I can't remember. And then I did four years at Thomas Delarue School. That was really daunting.

We'll come on to that if we may, but just to return to the brownies and the guides: how many of you who were at St Margaret's belonged to the brownies first of all? Approximately.

I don't really know. It's not a question that I can answer.

And so you met, did you, sort of after school?

Yeah. I mean we played but play is limited as you know, and play depends so much on who is with you because if you play ball games you've got to have somebody who can catch the ball. I think quite a lot of our learning was just sitting in the garden enjoying the garden, you know, but because it was such a big garden and because

there was such a lot of trees and things like that and people wandering about, it wasn't really boring. I mean, what you've got to remember is it was [a] totally different lifestyle to what people would expect today, because I don't think we really questioned enough. I mean I certainly didn't feel deprived but a person today might feel deprived because there wasn't that much going on, you know, not in terms of what there is going on today.

And as a brownie, what day of the week did you meet?

Well, at St Margaret's that's a difficult one, you know, we just did, and we more or less did as we were told. I suppose the great thing was the Saturday afternoon because that was when we got the garden scouts and brownies and what have you would take place. So that was on a Saturday afternoon, and Sunday of course was possibly church and possibly not church, but really there wasn't an awful lot of spare time. If there was I don't remember it, and I don't remember being bored.

Do you remember listening to the radio in the evenings at all?

Yes. More so at Delarue because at Delarue I had my own radio, you were allowed to take your own radio and that was a Godsend to me because I used to listen to the radio in the week and at weekends because I just couldn't stand sport on television; just sit there in front of a television for a couple of hours would drive me up the... I mean, television in those days was not like television today, it wasn't as interesting. It was a bit... If you were a sports fan and you watched Grandstand on a Saturday afternoon, which seemed to be the only thing that the TV was tuned in to, that was fine. By all means watch it if you enjoyed it, but personally I didn't; I'd go off and read a book. I was often on my own in a room and read, particularly at Delarue because it was just so much easier to do your own thing and to keep the brain ticking over.

And as -

Because that is very important to me. I may not have done O-levels or A-levels or anything like that, but my thirst for knowledge is quite something, it still is. I still like going places; I still have an enquiring mind. It probably wouldn't get me through an

exam, but it's helped me immeasurably when dealing with people because I can see people's needs before necessarily they can see them themselves.

And at St. Margaret's, Dorcas, reading, you say, [was] one of your favourite activities; what were some of your favourite books that you discovered at St Margaret's?

Well. Some of my favourite books were those that were read *to* us, because you can remember them. I was heavily into The Secret Seven, Biggles, that sort of thing, because we could get them. Art books even, which I'm still interested in, although my knowledge of art is increasingly expanding as I've got older. One only necessarily knows, when one's between seven and 12, what one's told. One doesn't necessarily go on investigations of an art gallery and sort of say, 'Oh, I like that, didn't know that existed,' you know. But I've always been interested in art and I certainly read art books and know why I like something or why I don't like something.

So the books at St Margaret's, where did they come from?

St Margaret's had some books belonging to it. I'm not quite sure whether people gave them, whether they had grants from the Spastics' Society to get these books, but quite a lot of them were local.

[End of Track 4]

Tape 3 Side A [Track 5]

Books for some disabled people posed a problem, because how did they turn the pages? And I mean even in places like St Margaret's there weren't page turners; they weren't even thought about. I could turn my own pages, have always reasonably been able to. I don't know what I did when I was very young but I certainly, almost at the time at school because books interested me, devised a way of doing it. And also I think some people had great difficulty controlling their head movement or controlling their eyes to read anything. I mean my friend who I went on holiday with who was at Thomas Delarue with me, he didn't like reading, he found it incredibly difficult. You know, he'll read the paper vaguely, but he didn't really like reading. And I think some people do find it incredibly difficult whereas I feel very lucky; it's always been an absolute Godsend to me that I can read cos not so much since I had the computer, but I've always had books.

And, of course, when you are at school these were in the days before books on tape or CD as well. And people visiting you from time to time, you know, looking at how the school operated and 60 or so children there when you were there – where did some of the other children come from as well then?

All over England and Scotland and Wales. A lot came from a long way away, and we even had some from abroad. You know, because you're talking about the very start, almost, of realising that people were... you're almost starting at the start of special schooling. Which seemed right at the time and I've had various discussions since I've left school, about access and how teachers react. And I can understand both sides of the coin. I can understand why teachers would find it difficult to accommodate some disabled people into a class, with what I call able-bodied people, would find it very difficult because they just don't have the time. And because the classes are so much bigger in ordinary schooling to what they were when we were in our special school. I mean 12 was the most and it was very often less than 12 people.

You started off with Miss Evans, and what other teachers did you have at St Margaret's?

I don't think I can add much more to what I've already added.

OK. So just to return to the brownies and the guides idea, did you work for particular badges? Was that how it worked?

No, we had school uniforms.

Yeah, you say you didn't train to...

You had school uniform. But bearing in mind you were taken to most places you didn't have to arrive there unless you could propel yourself and get yourself there, you were taken there by a member of staff. So all you had to know is where you'd got to go and since they didn't move us much around, you know, once we were in the class in the morning we stayed in that classroom until dinnertime, unless we had to move for whatever reason we had to move, we did everything in the class. We were put... Erm, yeah.

What did the uniform look like?

Well, if we had art, we didn't go to an art room, the art came to us. So in other words everything would have to be set up around us, which probably for something like art meant we had two lessons together, two periods together, which would give us about roughly a period and a bit of art, because by the time they'd set it up... you know. But I mean that was at St Margaret's. Because it worked. It worked. And the same sort of thing about the classroom. Everything was big, but was visual, like posters, weather, dates, nature, anything we'd see, what countries we was doing in history, geography, you know, all that was on the walls, which made it more living. It wasn't a dead subject; none of them were dead subjects. I mean, even needlework wasn't a dead subject, I mean it was lethal because of sticking one's needle in oneself, but it wasn't a dead subject, you'd do it on a cushion so that all you did was stab the cushion rather than stab yourself.

So for your lessons then, you generally stayed in the one classroom and you had the same teacher for the different subjects, did you? Is that -

Yeah, well yeah. We had the same teacher, we just did different things. And I mean I think that's what happens in primary schools anyway. You don't get different teachers. I mean they taught us everything, they taught us religious instruction as well, you know. I don't remember if there were any extra teachers for anything that Joy Walker didn't teach.

And John Walker, who was he?

Pardon?

You mentioned a name there? What was the name, sorry?

Joy Walker.

Joy Walker. Who was Joy Walker?

Joy Walker was a teacher.

So she was the second teacher you had after Miss Evans was she?

Yeah. Seven till 12 at St Margaret's. And she did the whole lot.

Oh I see. Yes, so you had Miss...

All the whole lot.

So you had Miss Evans, then you had Joy Walker, was it?

Yeah.

So in wearing the uniform then at St Margaret's, what colour was that? What was it like? Did you have school colours?

I think it was, yeah I know what it was: grey and red. Basically grey with the badge was a red S and M together. I think we just had one basic uniform for when we went out and about. I don't think we were in uniform all the time, not like they do now where they just have jumpers and whatever or skirts or whatever, which they seem to wear all the time. I don't think we did that, I think we had just uniforms for special occasions, because callipers and that used to get through – we used to get through no end of clothes cos they just used to catch on the clothes and ruin them completely. I mean clothes were quite a problem when we were wearing callipers because you can ruin them in the short time poss [possible], you know.

And you were wearing callipers, Dorcas, during the day. So how were you able to get about?

Mostly by staff pushing me from where I'd got to go to where I'd got to go.

From a wheelchair?

I don't ever visualise that it was a problem, but maybe if I went back now it would be, because I was not used to the outside world at all, because I was used to living with my parents and with the family, I wasn't used to going out and about. I mean, dad used to take me out, yeah, round Wellingborough occasionally, but not all that often because he was busy. Mum took me out to our aunties and uncles but not... I mean I can't tell you when I first went to the cinema or anything like that, which people do automatically now. I mean it's a bit like saying I once met somebody who was disabled, not with cerebral palsy but with something else, and he hadn't been out for 15 years because he had a hormone disease and he was six foot six tall, and they couldn't find a vehicle, unless it was an ambulance, that he could get into. And at the time the only people who had ambulances were the ambulance service, and you couldn't expect an ambulance service to do anything social, you know, with anybody; ambulance service is what it says it is. Ambulance service is for people who need to go to the doctors or hospital. They did take him to a friend's wedding. But, I mean, I have spoken to many school groups and I have said to these school groups, I've said to them, 'Can you imagine what it's like not being to go out for that length of time?' And they find it very hard to imagine that because that's almost the whole of their

school life. And they go to school and come out from school. They can't visualise what it's like to be stuck. And although I went out and about when I was at home, I didn't really go out and about when I was anywhere else. And, you know, it is very difficult for people to imagine something that they can't get their head round.

And so there you were at school, well we'll come on to the Thomas Delarue School shortly, but with other children of your own age with disabilities, with cerebral palsy in particular obviously. Do you remember really when you perhaps first realised, if you like, that you yourself had a disability as we would now describe it?

I must have realised as soon as I went to a school but I don't actually remember that. What I remember is going to Delarue and growing up to become a teenager and suddenly discovering that I wasn't an average teenager. [Laughs.] And I think that is when you start to realise what the differences are in your life. When you're growing up you don't necessarily know it cos you're having adventures as you're growing up, you're sampling new things, perhaps not at the rate that other people sample them, but you've got no yard stick. And then suddenly you find a yard stick which you measure things by and you suddenly realise just how without you are. And it's horrible that is. I mean I think possibly the worst time of my life was growing up, teenage years. Simply not because they were any worse than anybody else's, cos I think some people fly through it and other people have a horrible time. But I think it was just the attitude that was going around at the time: 'You can't do this, because of this. You can't do that, because of that. You can't get married, nobody'll have you, you're disabled. You can't go to work. You can't hold a job down.' And those are things that really impinged upon your mind. Tremendously so. And you think well, that is what makes you more disabled than you really are because people can throw those things at you and because they're supposed to be wiser than you, and because you're on a learning curve anyway, you tend to take more notice of them I think than you should do.

So at the age of 12, on the verge of changing times, shall we say, came the move to Thomas Delarue School. Just describe the set-up for us there then, of Thomas Delarue.

That again was an old house that was given by Mr Delarue, who I met, OK, and I'm still in touch with his son. His son rings me up because his son has, [inaud], you know. Great place for learning, secondary mod [modern] and grammar. Unfortunately myself was lobbed in the class where it didn't really matter; secondary mod, bottom of the stream. Got all the teachers, got all [who?] hadn't got anything else better to do and got different maths and English teachers practically every term, not quite every term but with different ideas about how things should be taught, they would be constantly swapping ideas, and it wasn't [nice?]. There was nine of us in the class so there was less of us in the class, but there was nine of us in the class with perhaps only one person that could pick things up if we dropped them. So you didn't drop anything unless you had a mishap and dropped something, because there was nobody to pick it up and it was always the same person that had to pick the things up. Particularly if you dropped things in prep. It was different if you were in class, if you were in class then somebody – the teacher or somebody – would pick things. There was no classroom assistant. Occasionally we had what was known as an amanuensis – a person to write for you. I used to write with a stick, with a pencil held in my mouth, and I used through books and books and books of writing paper cos it was fairly thick. And I was quite glad when the school moved on to electric typewriters which IBM reconditioned and gave to us, cos that was wonderful. That meant I could expand my word power tremendously because I couldn't write words like 'wonderful' on one line of a paper. Well I can now a lot easier, but then I couldn't. And so my words, my written vocabulary was very small; it had to be to get the work done.

So how did you begin to learn to write, you know, using a pencil in your mouth?

I don't really know, it just happened. It was a way of doing something and you do find ways of doing something, and it was an absolute Godsend in a way cos it meant that I could actually put things on paper, rather than carry everything in one's head. I was rather good at carrying things in my head but I'm creative as well so I like to put things down, and so I did put things down in writing and then put things down on the typewriter. Maths I found particularly hard cos the typewriter worked the opposite way to what maths work, so I was never very good at maths. And what I found was the biggest problem; they suddenly had this brilliant idea at Delarue when I'd been there about three years, to suddenly start us off on French, algebra and geometry. I

mean I was 14 and a half, nearly 15 at the time, and I couldn't cope with it. French wasn't too bad but the algebra and geometry just flew right over my head. Now if they'd have taught me that when I first got there it might have had more sense. But it certainly didn't make any sense and still now it doesn't really make any more sense because I've never used it. It's not the sort of thing I need to use. And, to me, unless you're going to use it, is it really practical to try and teach somebody that when there's difficulties in putting things down and other difficulties, which make it really hard to learn and really hard to grasp so that you don't get the hag of these things? And you get more and more frustrated because you see other people at school doing O-levels and A-levels and you're not even doing anything, so in that way, and I think the headmaster was biased towards people that could produce a good record.

So when you went to Thomas Delarue, having had the sort of grounding of subjects at St Margaret's, did you go there with particular favourite subjects in mind?

No, I don't think I did. I don't think I went there with any preconceived ideas at all. I don't think my mind was even formulated at that point. I think my mind formulated an awful lot in the four years that I was there; I grew up on some ways and not in others. But it was much more adult, much more adult. The teachers were really adult, we got told off, I mean you got told off at St Margaret's but not in the same way. You had to make many more decisions; you had to get on with people I should think. What amazes me the actual fact that Northants county Council, which was reputed to be one of the meanest county councils at the time there was, actually paid for me to go to Delarue because the fees were similar to Eton. I mean I imagine the fees at Eton are more now, but, you know, the fees were really high. Again it was in magnificent grounds, not quite so mature or interesting as St Margaret's; St Margaret's was interesting and it was interesting because it was beautiful, it was peaceful, there was so much to see, it was a mature garden, it had everything. But Delarue had nice gardens but they weren't... I think because again we were growing up our interest, likes, was spreading. I mean, when I was at Delarue I practically read every book in the library including the Encyclopaedia Britannica. I was very much a loner. I liked, I enjoyed the Beatles when they first came out cos they just hit the headlines more or less when I was at Delarue. I enjoyed reading at night. I could get the house mother to put me into bed, so I lay on my stomach with a pillow under my chest and read a

book. Even if a book was only two inches away from my eyes! [Laugh.] I still managed to do that. Again the food was not as good as at St Margaret's, we had some horrendous meals. We had funny meals, what I call funny. They used to do ham with caper sauce, which are like peppers, but it's capers. And it was horrible, you know. And we used to have rice pudding which I detested. It was either solid and you could cut it, or it was floating about in hot milk which again put me off. [Laughs.] You know, I could stomach tapioca because the tapioca was a totally different taste in the milk to the rice. And I didn't like rice in milk and I didn't like macaroni in milk. Give me macaroni cheese and I'm OK. Give me rice that isn't sweet and I'm OK. But give me rice pudding without anything with it, and I yach, generally be ill. And they used to have things like pears and sometimes they'd buy cheap things, and the pears used to be so stringy they were horrible, they were just like mice and a load of string, you know. And we'd have blancmange and again that used to do things to me, you know, I don't know why but some of the things were so bad. You'd ask for a small one and some people just out of sheer perversity would give you a bigger one, and I think that's very unfair because if you don't like something, you don't like it. And, OK I know many people have been forced to eat things they don't like, but I don't think it does anything because if you don't like it you don't like it, you know. And the dining room was a very plain room with just tables and chairs and spaces for wheelchairs, with a very functional floor that could be washed every time we left. The tables had all got Formica on the top so that they could be washed, the chairs that people sat on were Formica as well, plenty of people had mats that they could put their plate onto to stop them sliding around, and collars to keep the food on, which they still have today. I used to feed myself then but I've given up since because it is hopeless. I never got a hot meal, food went flying on the floor and well, and it took me ages to feed myself anyway, and it was one of those things that made me more disabled than I am. And I think sometimes you have to make decisions about those things: am I going to do it or are people going to have to put up with food flying around because I can't do anything about that, and if that is the case, is that going to make me look more disabled and make me look absolutely not with it. And I came to the conclusion that it made me not with it and that certainly when I was at home I couldn't put food all over the place because my mother would have to clear it up and there were carpets, there weren't shiny floor surfaces that you could mop up or sweep up easily. And decisions

like that have to be made I'm afraid, whether it gives up your independence or not. That was one decision I really made, and really was quite grateful that I made it.

And never a hot meal because of the time it took you to...

... to feed myself with it. A lot of it was so messy. I think it was just messy. And I hate being in a mess, any sort of mess, you know. I think well if I was able-bodied I wouldn't be in a mess so why should I be in a mess when I'm disabled? And I think people do go by how you conduct yourself, tremendously. I always try and think of that when I'm doing anything.

And at Thomas Delarue School you were at, or near, Tunbridge in Kent. Did you have much contact with the outside community?

No, very little. Back in those days to get a taxi to share with two other disabled people and one house mother, which we were very lucky to get, actually cost us 50 pence or 10 shillings. Ten shillings back in the fifties was about as much as we got for term. If I can give you sort of price indicators – price indicators was sixpence, two and a half pence for church, and possibly two or three pence (which would be about tuppence), a penny for guides or brownies or whatever, well I was a guide there so it was guides. And, you know, we did have a tuck shop and we did have to buy things like tissues if we had a cold and all sorts of things. So if we didn't have any or... I remember spending a vast majority of money on tissues for colds because I had loads of colds. I think that was because I was growing up and I wasn't particularly happy there. I didn't feel that I belonged like I felt that I belonged at St Margaret's. I didn't feel that I was more necessarily wanted either, which is really difficult and it's difficult to explain to people why I felt like that but I did.

And did you, you know, come to have particular teachers or people that you could relate to better than others?

My speech therapist (because I did have it for a time because I had so many colds and they wanted to teach me to breathe properly, which plays a big part in how you speak and diction and everything) was wonderful. Her name's Elizabeth Oliver – the speech

therapist – and I’m still in touch with her. The art person was absolutely wonderful. She taught me a lot more about art which I very much appreciated. But we did have different teachers. As I said, English and maths we had a different teacher frequently, which didn’t exactly help the learning curve on maths or English. History and geography we had the same teacher all the way through, and you can progress like that because they take you from one bit to the next.

[End of Track 5]

Tape 3 Side B [Track 6]

I knew him when he moved off from our school; he moved to the Star Centre down in Cheltenham, and I went and gave them lots of talks, I've given them lots of talks in my time about enabling disabled people to plan things and do things themselves. He was wonderful because he was intensely practical, and he taught us science so that we would know what to do when the television packed up. What could be wrong with it? How to change a plug, how an iron works. How do these things work? And he showed us without us having to fiddle around and do experiments that we knew we couldn't do. And he was no danger because he was doing them.

And the art teacher's name? What -

The art teacher was Joan Armitage. She's been married since. I haven't kept, I sort of have been in touch but I haven't been in touch lately. She was wonderful. She also, not just physically doing art, but talking about the history of art. And got pictures for us to look at: [inaud] pictures, posters. There was an actual organisation at the time that did pictures which they lent to schools, which are actual copies of actual pictures, but they can actually be hung up and can actually be seen and have notes about them, so that you could learn. All famous paintings mind you, most of them were famous paintings, but it was very interesting. Music was good as well. We also had a form teacher who was there if we had any problems and that used to change every year. But we had religious instruction, we went to church; the whole school went either to the Church of England, well basically to the Church of England, but if you wanted to go Methodist you could go Methodist. Church was a nightmare though because once again there were a lot of us in callipers; we all sat at the back of the church and we all creaked together. The matron used to go off to sleep; she used to start snoring. We were so far back because it was [a] very big parish church, we were so far back we were the other side of the central aisle, as far back as we could get all together and we'd all creak together, and people used to turn round and look at us – you know how people do when you make an involuntary noise or if anybody comes in late – and to me that was a nightmare because one always imagined that the callipers or whatever noise you made sounded quite as loud to you, and you always imagined that everybody heard it whether they did or didn't. Mostly didn't but I mean... In the end

it used to be quite nerve-racking because if you make a noise and several other people make a noise, you begin to get more conscious of the noises you're making than what you're doing at church. And so it became a nightmare.

And so how far away was the church from the school?

Yeah. I mean, oh it was about three mile. We had to go in a coach, you know, we all had to be loaded up in the coach and unloaded the other end. It was no easy task. At this stage we began to have proper wheelchairs, you know, rather than wooden seats and things like that. But again the wheelchair seats laced up underneath, they were very sort of basic. And I don't think they were possibly as good because they weren't supportive in the right sort of places and of course that didn't help, because you were almost inclined to sag. Even with callipers on you can still sag if the seat sags. So I think the wheelchair industry's come along a lot further but I still think it needs to come on more, because I still think posture and how comfortable you are, and I mean I can sit for 18 hours a day, I need to be comfortable. And the older I'm getting the less comfortable I seem to be, and the need for the right sort of equipment is much more obvious now than it was then.

And, you know, you had full days during the week with various lessons. Did you then have much homework at all?

Lots of homework. I mean we were given a lesson and the rest was homework, you know, what we learnt at the lesson had to be done at homework. It was very much more pressurised. Homework comprised of Saturday morning: the first half was homework, second half of Saturday morning was writing home if you wanted to, and you really had to. And it was much more a question of doing it because it had to be done. Lessons really depended so much on... We'd have a full time lesson; we'd have an hour a day between four and five between coming out of school and going in for tea, and that was our hour's break. And I very often just used to go outside if it was sunny, listen to the radio or stay in and read a book or queue up for the loo, because every other minute of the day was patronised. Not intentionally patronised but patronised enough not to leave you anything, not to leave you any free time. Weekends; Sundays was church in the morning, Saturdays was sport in the afternoon,

Saturday mornings was prep homework like they did at all boarding schools, and the weeks were more or less the same. You ask about visitors; we had lots of visitors to see the school, but we only had one lot of visitors. One doctor that knew us from going to the same church used to invite me out, because she realised that I needed that, I needed to get out and away from it. She was brilliant. I mean she's died recently as well, but we kept in touch until she died. And the Toc H [a community-based charity] used to take us up the road or down the road in countryside because we was three miles from town, and push us, and that was as much as we did. If we were the grammar side of school or if we'd done anything really special, we were invited to go out. I mean the county guides used to take us out to a party once a year, the Gilbert and Sullivan Society of Bart's Hospital used to take a coach load of us once a year to London to see their production; I only ever went the once. The rest of the time – you didn't all go, only select people went. We had prize day, yes, and people came up for that, but we weren't allowed to go home with them or anything like that, they had to come and go. And I think that's about... Oh, and then the guides and the scouts came; that's about all the outside contact we had.

So the guides and scouts came in from outside, again?

And, you know, some of the housemothers were local but I mean we never got invited to their places because they worked there and it wouldn't have been viable; if they'd have done it for one they'd have had to have done it for more than one. That didn't happen. So really, once again we didn't meet many able-bodied people.

You mentioned a doctor. Was that Dr Lewis that you mentioned, that you were in touch with?

Yeah. If you were poorly, matron used to send for the doctor. The doctor used to come. The doctor actually held surgery quite often, and if you were really poorly you went to hospital.

And where did she take you then, the doctor?

Well, she'd either send you to Kent & Surrey Hospital, or she'd send you to the local hospital at Maidstone. I ended up there once. It could be anywhere depending on if you saw a surgeon and where the surgeon was based and what hospital he was based at and all sorts of things. And they never really came with you, they packed you off. I mean I had a bad asthma attack once and I was absolutely scared out of my mind cos by the time they got me in the ambulance it was dark, it was a pitch cold winter's night and they drove miles through the countryside in this dark ambulance with nobody that I really knew. I was really panicked by the time I got... Luckily it was a cottage hospital and the cottage hospital was superb because they realised what had happened and sorted me out. But, I mean, you go to a big hospital, you end up explaining that you need feeding and that you need toileting and that you need dressing because hospitals haven't got a clue.

How old -

They'd got more of a clue then; they've got even less of a clue now.

How old would you be then, Dorcas, when you had the asthma attack?

Well, most of the things I think I had done I had done when I was at Delarue. By that I mean most of the journeys that I made were to local hospitals while I was at Delarue, well, hospitals round about while I was at Delarue. Since I've left school I've kept reasonably healthy but I have had a few spells at Kettering's Hospital and there's a few stories attached to that, but that wasn't when I was at school. When I was at school I used to have to fend for myself. But because I fended for myself when I was at school, it wasn't that much different except there were people that you didn't know, but sometimes people that you don't know are easier to communicate than those that think they know it all.

And you mentioned you went out on trips with the school doctor. Where did you go?

Not many, not many; mostly to the guiding events which were held once a year. I mean I don't think we went out for many trips at all because there was too many of us – there were 99 to 100 plus of us at Delarue. We used to go swimming and that was

on a rota basis, you either went swimming or you didn't. I mean, for the more athletic sporty types it was virtually every week but to people that needed undressing and dressing again it was once in a blue moon. I don't remember going that often and I don't think I did go that often. I did participate in the swimming gala, I did get a medal for swimming a width, but I mean I wouldn't say it overjoyed me.

And when you were at Thomas Delarue, did you strike up particular friendships with people?

Yes, I got on quite well with quite a lot of people. I am still only in touch with two now because people move away and you move and, you know. Sorry, I'm in touch with four. Two by letter which basically is Christmas only; Ann I meet up with on holiday the week before last, and a friend who shares the same birthday as I do in Wales who is very disabled, who's just gone to live in a home. But I feel really sorry about that. Obviously it had to come to that because she lives in a very rural part of Wales and I don't think she could manage and I don't think she particularly wanted to manage. So yes, I am in touch with a few, but I wouldn't go back to any reunions; the prospect rather puts me off, rather than encourages me. I mean, I get on very well with the people I'm still in touch with, very well indeed. But I had so many, I think I was quite a loner while I was there, I really... It doesn't hold many... It's not the happiest time, you know. I mean, yeah, I enjoyed the learning because, I come back to that, I really enjoyed learning, but that doesn't necessarily mean that you have a happy time totally. There was too much made of the people that made it and nothing was made of the people that didn't, and it made a distinct division in the school and the way that people reacted towards you. What you did, if you did lots of things then you went lots of places, whereas if you didn't do a lot of things they didn't really want to know. You know, you would just plod on.

And so when you think of, you know, a term as opposed to being at home, did it seem a long term? Thinking back now.

I don't think so because you're doing and learning. The learning bits didn't seem long at all, but the bits like Saturday afternoon when I made my own entertainment, and when I very often got forgotten and left in the classroom because nobody knew I was

there, seemed forever. Or once or twice that I got left on the toilet and people forgot I was on the toilet, I couldn't get out because of various circumstances, and sat on the toilet for about three, four, five, six, seven, eight hours before somebody realised. They were all bad experiences. Things that if I was running the school I would certainly try and treat everybody equally and try and make sure that people didn't get left, and didn't get left out, and if they did get left out, try and work out something what they could find interesting to do. To give them more of an equality feel, because I think that if you give people equality, or a better quality than what they're possibly having, it helps them tremendously. It really helps because they need that boost. They need to be able to sit, say that somebody's cared, that somebody's bothered, that somebody knows what they're going through. I mean I had ever such a job when my parents were told that they could adopt and then they were told they couldn't adopt because I was disabled; that happened almost as soon as I got to Delarue. And I couldn't tell anybody about it because the school was such a hot bed of gossip in a way; I don't mean gossip but if you told anybody anything it was round the school in five minutes. And I don't mean pupils, I don't mean students, I mean staff. And so you never really told people anything because you just didn't feel necessarily safe doing so. And I think that is why there's an awful lot of problems sometimes staying school because people don't say what's wrong.

And so did you share confidences and experiences, you know, with your fellow pupils?

I think so. I know my fellow [pupils?] agree with quite a lot of what I just said, and I think with others as well. But I think it was to do with an era in his, an era rather more than it would be today. I don't think you'd find the same situation at all. And certainly with what I've done since school, I wouldn't have gone through it in the same way as what I did go through the last four years, because I'd know how to deal with it. But it was not knowing necessarily how to deal with it, and having to be content with my lot.

And so, you know, as you made your way through Thomas Delarue, you talked about the arrival of reconditioned typewriters. When did they then become the major way that you wrote?

No, nothing happened until I left school. I was still very immature and very lacking in lots of things. But I was very lucky because my father had realised I think something of what I was going through, and he read in the local paper that there were going to do a Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] course the summer that I left school, and he put my name down. And that was to change my whole life completely and irrevocably. It really did. It made me aware of so much that I was unaware of before. I don't say totally unaware but which I'd blissfully, not ignored but not paid particular attention to. And that was a challenge to me. The last year at school just made me so unhappy it was incredible; I had to go. Because if I hadn't gone I'd have cracked. I know that and I think they knew it in the end as well. You know, because I just couldn't tell anybody how I felt. There wasn't anybody that I felt safe telling anything to anyway, which is quite sad. I don't blame the school because I enjoyed the learning, but I wish there'd have been something somewhere, and that's why, when I do anything, or everything that I've done since has been to make my position clearer. But, being disabled is not the end of the world; it's just a new way of thinking about things and a new way of looking at things and a new way of enjoying oneself. Because I now think, because after getting over leaving school in the way that I did, I never didn't accept my disabilities – disabilities didn't come into it – it was just lack of being able to say how I felt that was the major stumbling block. It probably wouldn't have happened if I'd have stayed local; I would have probably had much more conversation with my parents. But my father realised that I was growing up and of course, because he made that decision that I would meet able-bodied people on this Phab course – physically disabled and able-bodied people – he made the decision. I went and had the most wonderful time. And that time changed me forever.

So in, you know, conclusion of the Thomas Delarue School, there was no talk of putting you in for any kind of exams of anything of this sort?

I wasn't clever at anything. I mean, no I wasn't clever at anything. I enjoyed reading, I enjoyed art, but I wasn't clever. I enjoyed anything to do with learning apart from maths, which I thought was a total waste of time, I mean apart from adding and subtracting, multiplying and division which I don't think is a waste of time, I do think

maths is useless. I mean, it's just like a blot. You know, you get these blots, you can't do anything about them, it seems ordained that you're good at some things and hopeless at others, and maths is one of my hopeless things. I mean we had to do everything in our heads anyway and put it down on paper, and I could do that, and I can still do that. The last term I was at school I think they had adding machines, but they certainly didn't have calculators. I was never brought up on calculators, I was brought up on literally hearing somebody talk about maths, understand what they were talking about, being told to work things out – which is vastly different from how things are taught today. It was the same with all the subjects basically. Luckily my interest in reading meant that my English wasn't too bad, and I found English quite interesting. I've read all the classics since, but I didn't read the classics when I was at school. I might have read some of them and I certainly read some jolly good books when I was at school and had some jolly good books read to me which I can remember now, and which I've read since, but I don't... Academically I was a dead loss.

The calculators were, I would imagine, mechanical calculators which were the predecessors to electronic calculators. What were some of your favourite books then, from that time?

Rosemary Sutcliffe's *Eagle of the Night* – brilliant, it conjured up my imagination. It meant something to me because I knew of Roman history. It was very well read to us. *Silver Chalice*, that was based on somebody knowing our lord. Fiction, but still equally as good and very positive sort of book. *Little Women*. All sorts. The Dickens novels which I not only had read but saw on television; all the classics. Classics like *Jane Eyre* – they're a bit girly but I still like them; I think they're fantastic insights into people's lives of the time, and I like that sort of thing. One of the reasons that provoked me for writing anyway but partly because when I'd done Phab so many people said to me, 'You've experienced these things, you've started Phab up in your own area; why don't you write about it so that other people can realise that they are able to do these things, that disabled people are not people who should be put away, forgotten, they're living, breathing, normal people – well, whatever normal is – but people full stop.' Real, I should say, perhaps real is a better word. And I thought about

it. The first book took me seven years to do, basically because every professional that I talked to about it wanted a sob story.

This is the first book of autobiography that you wrote.

Well, it's called *Opportunity, Not Pity* and that's the first one. The reason why they wanted a sob story was they couldn't conceive that me being disabled was happy. They couldn't conceive that my life was enjoyable once I got myself sorted out, after doing Phab and realising that I could do things with able-bodied people and we could go out together and we could go to the seaside for the day, or we could go shopping and we could go have a picnic. Anything. And transport could be got round if one... I raised money for vehicles. I got the vehicles. And then I found a driver and then he took people places because people hadn't been to that many places and a lot of disabled people's families don't drive because they can't, again they didn't vision themselves in that sort of situation. And sometimes they had to work which meant the person who was disabled was left out completely.

Phab – Physically Handicapped and Able-bodied, as it was originally conceived. Now we'll perhaps come on to that in more detail next time, Dorcas, if we may? Interesting to explore. So when you [were] at school, finishing then perhaps, sailing through rough times as perhaps you felt; did you, especially afterwards, looking... Oh hang on; sorry we're just about to run out of tape, actually. Shall we just pause there?

[End of Track 6]

Tape 4 Side A [Track 7]

So there you were, you know, coming towards the end of your time at school, and you referred earlier to kinds of messages that you were getting from your time at school and from that time of your life. Where were these kinds of messages coming from then, really?

Staff. I don't think the students bothered one way or the other. But the message was coming from the staff and some quite senior staff. And that really did worry me because I thought that they knew something that I didn't know. And I thought, 'Am I really wanted here? Do I really want to continue being here if I'm not wanted?' And because I was a loner I think it got me by the scruff of the neck, you know, it became a real big problem which I couldn't talk over with anybody, and because I couldn't talk over with anybody, it sort of took over me. And in the end I just said I can't, because obviously, having met the psychologist and having had the thing at 16 and a half, which is when you can leave anyway, I just wanted to be out. I didn't care whether I worked or not to be quite honest. I mean I probably did at the time but I don't think I did; I just wanted out.

So you had an assessment did you, towards the end of your time there?

Yeah, you have an assessment. I just thought, 'Well, why should so much be paid out for me to come here if I'm not really happy and I'm not doing anything, and I want to go? I want to finish.' I don't think they understood how much they affected that decision. I'm sure they didn't. I'm sure they had no idea that they were the ones that planted the seed and the seed grew into a great big problem.

So, you remember feeling, you know, unsettled, unhappy at the time as well?

Yes, very much so. Very much so. I feel less unhappy about it now, but at the time I felt absolutely devastated. I thought if I don't get out of here I'm going to crack. I think I came to as near as cracking up as I've ever come. And I'm not the cracky-upy type. I can cope with things if they're thrown at me so often. But I just couldn't cope with that. I think it was because I felt more and more isolated, less and less wanted,

and couldn't see where I was going. I mean, I couldn't see that anybody was going to give me a job because I'd been told that, and I just felt so out of place. But then, at the same time, I knew there was more to life than what I was getting, but I didn't know what. And it wasn't until I left school that I discovered what it was that I was needing or lacking. And I couldn't have said at school what it was, because I didn't know. All I knew was that the big white chief – that was the headmaster – and his wife had said to me: 'Oh, you're feeling upset, then. When are you leaving?' And a simple statement like that, which wouldn't bother me these days, really upset me then.

And so there was no particular mention of, or questioning, asking you what you wanted to do next or...?

Oh yes they asked me. I said I'd help dad, because there was nothing coming from them, so I had to provide the answer and the answer was, oh I'd do something to help dad. Whether dad knew that I shall never know cos when I got home he set me off on a completely different tack and he sent me to Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] within me being home six months, and my life took a completely different tack anyway after that.

Your dad of course running a tobacconists and a gents' hairdressers in Wellingborough. So what year did you in fact leave?

I left in 1964 at Christmas, rather than at the break of term time. I'd just had enough. And I thought well it's not working, I don't have to go to school, and I thought of the money being spent as well that could help somebody else to go, that would possible be much more productive for somebody else. Because I've learnt an awful lot. I've learnt from past pupils that had been to the school who wanted to do, who had done O-levels and A-levels, and of course had got entwined with the education system. It's all very well to get entwined with the education system if, I mean, and it's nice to be learning, but some of them had got entwined with the education system, passed all their exams and were still no further than I was. You know, it hadn't given them what they'd hoped it would give them. I mean I had a friend who has very bad speech difficulties. She wanted to be a judge. She could have easily been a judge cos she

qualified for all the exams and everything, but she couldn't be a judge because she's got a speech difficulty and nobody could understand her. But instead of somebody talking to her about it and trying to make her see that perhaps she could be a backroom person and equally have the qualifications but equally be useful, nobody ever talked to her about it. Consequently she got herself in a state about it. And I didn't want to be as useless as that; I wanted to do something and feel that what I was doing was useful, maybe.

So how extensive was the end of school assessment that you had then? What kind of areas did they assess?

Well they test your IQs for a start. They ask you what you can see in patterns and things and all sorts of weird questions, and what you intend to do with your life. And to be quite honest, school didn't prepare me for anything. Not what I wanted to do. Because I could have said pie in the sky things which wouldn't have been achievable. And that to me is... You're much more able if you can cope with what you want to do is cope-able. You know, if you can do something, set your stall out, have an achievement and achieve it. One-up. And it gives you satisfaction and it gives you a lot more than struggling to do something which you can't achieve. A goal. And I've had enough of being told, 'Oh, you can't do this because you're disabled.' I know I'm disabled. I know exactly where my qualities are and where I'm a pain in the backside, thank you very much. I think I've broadened out, and I know exactly what's troubling me if I get troubled, I can do a very good self analyst on myself, and I think I could even at school. And I think that's where I was going. I was going down a hill to nowhere. And I couldn't tell them, and I couldn't tell them what I wanted to do because I didn't know what I wanted to do. The only excuse I can give was that dad would give me something to do. I didn't think dad would, but I thought that something would happen and I would become a bit more definite about things and, you know, that would give me the answer. Jane's just drawn up by the way.

Oh, OK.

Is that OK?

Sure, sure.

[Break in Recording.]

Looking back at your time at school generally; you left in, what was it – 1964 I think, wasn't it?

Yeah.

How successful do you feel the teachers were in being able to assess your abilities or being able to use the technology of the time to help you?

The technology at the time was virtually non-existent. I mean I had an electric typewriter which, for me, was technology, and it was easier than writing things. But I had no idea that technology would go the way it has and I don't think they had. And I think I was born 20 years too soon. But I'm glad because my parents have shaped so much of me without realising it and without me realising it [laughs]. It's only over the later years, now, that I realise, since they've both been gone in a way, that they played a magnificent part of my life and helped shape me towards what I am now, and I'm quite content with what I am now. I don't have any regrets at all.

And, you know, you left school with the facility to enquire and to engage with things around you. So how, generally, do you look back on your school time really?

My home tutor and my middle school, St Margaret's, were the most successful time, and to a certain degree John Greenwood's, although I have less recollection of that because it was such a short time. My last school made me think for myself and fend for myself tremendously so, but it didn't really help me a lot otherwise. But school, yeah, I mean you have to go to it and I don't regret it, the only thing I regret is not having the knowledge to have been a bit bolder with the people when they were asking me things, or to have more of an outside view. Mine was a very closed-up view because I hadn't been about then enough to learn to challenge anything. And I think sometimes there's ways of challenging things which you can do without necessarily causing a great hassle and overdoing it. And I think if I'd have had a bit

more knowledge, bit more been about, done it, I might have got on a lot better. But I don't regret anything of it; there's nothing to regret. It's all past history. And you can't really live in the past; you've got to live for the future as well. You can only gain from the past by knowing where you went wrong. I think one should live every day at a time.

[End of Track 7]

Tape 5 Side A [Track 8]

Dorcas, at the -

Oh God, oh God. I've lost my... Oh no, stay there. I'm all right. Carry on.

At the Thomas Delarue School you had visits I think then by one or two famous people in your time there?

Yeah. The first term I was there we had Mr Pastry open a small swimming pool, which was heated, which rather reminded me of a very large shed with windows in it. Cos it was wooden and it was like a shed with windows in it but it was a heated pool. And people chosen to swim in it were people that had been at the school before I was there, well before I arrived, sort of thing, and Mr Pastry himself went in the pool – he fell into it which is typical of the actions of Mr Pastry. We didn't actually meet him; we only sort of witnessed what went on, I've got some photos of it. It was a lovely because he was quite witty and nice with everybody. [inaud] is not very outward. I mean he was pleasant to people, he could communicate to people whether they were disabled or otherwise, which sometimes people can't do.

And tell us – for those that don't know – about Mr Pastry.

Mr Pastry was Richard Hearne – that was his name – and he was a bit like Charlie Chaplin except he was more a clown than Charlie Chaplin, less stylised sort of thing. A bit like, who can I say? A bit like Norman Wisdom, but not in a cap; he used to wear full dress get-up with a top hat and bow tie and everything. But he was a nice man, he would talk to anybody, and he made a very good impression actually. But of course he went round with all the VIPs and it's very difficult when it happens about the first or second day you're at school because you don't know anybody and you just clap at the appropriate time and do everything like that, but I get the feeling that he really wanted to be there and he really wanted to see, help people with disabilities. It was at the time when they suddenly realised that swimming for disabled people was a good thing. The actual swimming pool was quite small so we only went swimming in it if it was part of our physiotherapy regime to help us. I don't remember using it that

much. But it was great because it was heated; it was great for helping people with asthma and things like that.

So I suppose in modern terms it would be described more as a hydrotherapy pool.

Yeah, yeah, definitely. I mean I think it was the early version of that sort of thing. It was certainly warm. I mean the swimming pool that I use when I go camping, that's a warm swimming pool and that helps lots of people. But that's an outdoor one; this one at Thomas Delarue was in indoor one.

And what other famous people did you...

Michael Bentine came and cut the ribbon to our first electronic door, which was to one downstairs classroom, and that was really most amusing because he didn't stay very long – I think he must have had lunch with the headmaster, and he must have met some people in between stuff and the whole school didn't see very much of him – but he cracked jokes and he was fascinated by the door which worked not by sensors like they do now, it worked by some sort of pressure. As soon as you rolled on to the mat, the mat sort of opened the door and the door would open, and when you got off it the other side it would close. It had not very fast timing, so I mean sometimes a whole queue could get through before it closed properly again. But it was the first one I'd ever seen and it was certainly the first one we ever had at school, and it was the only one we had until I left. I don't know if they had any more later on but it was certainly a good addition because, as I said, the buildings were quite old and the doors were quite heavy.

And so what sort of year would this be?

Well I'd been there about two years I think, two or three years. It wasn't at the beginning definitely, but it wasn't at the end either. I didn't know who Michael Bentine was though, and of course it was a very much younger Michael Bentine than what we saw sort of in later years. But he was very distinguishable, you know, you couldn't mistake him for anybody else [laughs]. If you once saw Michael Bentine on the television he was the sort of person he would come down the street and you'd

know it was Michael Bentine cos he couldn't be anybody else. And he had quite a booming voice and quite a sort of definite character. I don't think he was so at ease as possibly Mr Pastry, Richard Hearne, was. Richard Hearne seemed very at ease, he seemed as if he'd been doing it with disabled people and able-bodied people all his life, as if he'd dealt with lots of different kinds of people. And I think he had done a lot for the Spastics Society – Scope – I think he was one of their regular sort of people that... Hello! We've got... never mind. I think it's a bumble bee but it might be a wasp flying around.

How did you feel at school getting visits then from these famous people?

I think it must have been organised through the Spastics Society to give us a bit of high profile, to show what we were, what was begin done for disabled people. I mean I don't think we made the news every day; I think we only made the news like when anything special happened. The newspapers reported it and I think, certainly with the swimming pool, it got to television level, or radio level. I don't think the door opening did cos it wasn't sufficiently... It was a big event in that it was the first of its kind I think, but it was not as news worthy as a swimming pool would be.

And at school I guess another, probably annual aspect of the school was the speech day. What are your memories in particular of speech days?

Speech days were very good on the whole. I didn't get many prizes but I did get a prize. One event wasn't so good and that was the one where we were told we all had to think disabled all the time, we all had to think handicapped all the time. I've never done that in my life and to me that would send me in a downward spiral immediately because it's not positive, it's negative. If I think disabled then I don't rise to challenges, like I would do if I didn't think.

So this apparent recommendation to think disabled, think handicapped; that was then contained in a speech was it?

Yes it was contained in a speech, again by a consultant. And I was very surprised because I knew I was disabled and I knew what my limitations were. They were more

then than they are now. But I and some of my fellow students at school, I'm sure we didn't go round, I know I didn't go round thinking like that, and I talked to my friends about this and some of them didn't go round thinking like that. I know we were a bit protected from a lot of able-bodied people because we didn't meet that many people, but having said that I don't think that makes any difference whether you meet able-bodied people or not. You still don't want to think disabled all the time because it's just a bit, it's just so negative and it doesn't give you any sort of ability to strive for things that you want to get over.

So how did you take it at the time then, in terms of...

I was quite shocked that anybody in a position of a doctor consultant, a person who supposedly knew, was the in-person with cerebral palsy or the in-person with disability, had to say something like that. Because it makes disability so self-contained and disability is not self-contained in that way. If you're going to be that self-contained you might as well sit in a room and never meet anybody.

So...

And I was just so disappointed. I think, even though I hadn't known many young people at that age, only the young people that I was at school with, I found it very lacking in thought.

So the recommendation to, as it were, think disabled, think handicapped, you took that to be a recommendation then to limit your expectations, did you?

Yes, I think so. And I think a lot of things about that time limited one's expectations. One was told that one would possibly never work, one would certainly never marry, and you get these things dinned into you and told to you so many times that – by people you assume know – that it takes an awful long time to get rid of the preconceived ideas you've had that have been stuffed into you. And because of the way that the outside world reacted then to disability, which is very different – I mean we know that there's people around today that don't understand disability but there was more people then – and people always assume that they have a right to judge over

you what your actions should be. I would never judge anybody else. People are people to me. You know, you don't go around throwing judgements about because their life's completely different to mine, and I don't think you can judge people. I am fairly religious and it's a bit like judging, saying that you've got to crucify Jesus because he was Jesus. You can't go around doing that. I also get quite worked up when people have got such definite ideas that they just don't want to know anybody else's ideas. I find that awfully restrictive in a world where everybody has ideas and everybody should be able to express their thoughts and their ways of thinking. And I think it's much better if we do express our thoughts and ways of thinking, even if other people disagree with them, because I think that way you get a much more even world.

And you came home from school at the Christmas, leaving that little bit earlier. What were your emotions when you left school?

Great. Great because I was going home, sad because I was leaving a place of learning, because I like to [to] learn, but tinged with excitement because I knew that there was something out there. I wasn't sure what the something was, but I knew there was something out there, and I knew that there were going to be adventures, if you like, challenges, adventures, all sorts of things. And I knew that if I could make a few more young friends and get going a bit, I could gradually move forward and move forward in such a way where the movements were possible. Nothing I done was pie in the sky; I deliberately limited myself to things that I knew that I could possibly get there, so that I wasn't disappointed when I did. In fact I was more than pleased when I did, because I didn't want to reach for things that were pie in the sky because I knew that if I did that I should end up thinking, 'Oh why can't I do this?', instead of being thankful and saying, 'Oh I've done that, that was a good experience.' I mean OK there were some things that I didn't do, like there is in everyday life. But I have never been that disappointed, I've always had other thoughts and other ideas and other ways of looking at the problem, so that I've not been terribly disappointed. And I've been excited. I've been excited by the challenges that have come my way, I've enjoyed my life tremendously, I've come to terms with my disability. I think I came [to terms] with my disability the moment I left school, because I suddenly grew up. And I think one of the biggest assets about going to boarding school though is it teaches you to make decisions, it teaches you to stand on your own two feet, and those are all pluses.

The negatives from my point of view were that I was very fond of my parents but too fond of them, and I couldn't cut the apron strings like some people can, and the other negative was that I couldn't find people to talk to when I desperately needed people to talk to. I don't say that happened very often – it didn't – but towards the end of the time at Delarue it did, and it mattered greatly and I think that really coloured my judgement slightly of why I wanted to get away so badly.

And you say that when you came home from Tunbridge, back to Wellingborough, that you grew up. How would you say you grew up?

I grew up because it was more the real world; it was me in the world rather than me in a world where disability prevailed. And you learn to grow up. You learn that your disability is not the worst in the world for a start off, which I already knew because I'd already seen people far more disabled than myself, but you also learn that people who are able-bodied have major problems as well. And sometimes it's easier for people with disabilities to get the help that they need – or it used to be in those days – than for able-bodied people to get help. And able-bodied people suffer from loneliness and suffer from not knowing anybody who they talk their fears to, and really there wasn't that many agencies around at the time to help people. There's all sorts of agencies now; you can get almost help for anything if you're prepared to make the effort and look for it.

And of course, on leaving school, 16, 17, that's a particularly important time for peer groups, for meeting up with others of your same age, and you say you set about meeting new people when you got back to...

Well I met young people because dad was very encouraging to start off with; he was wonderful. He told people about me and I got involved with Wellingborough Youth Council, which in turn got me involved with some teachers, which in turn got me involved with what was locally round here as CSV [Community Service Volunteers] but is not the same as CSV today. What it was, was community volunteers in schools going out and meeting people and doing things for them like the shopping, like taking them for walks, like playing games with them or just sitting talking to them or doing their hair. But doing something to help somebody. And the teacher that was in charge

is – most of them are still around; well a few of them are still around. I was sort of secretary and I just sort of went around and kept the teachers in touch a little bit. But it was very important to me because it meant that I was involved; I was doing something. I also got involved with Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] which is physically disabled and able-bodied, which was also very important because there we had outside young people coming to look after us for a week. And the only thing that was rather distressing was the leader said that an engaged couple wouldn't be able to wear their engagement ring cos it would give us ideas.

So CSV, in modern terms Community Service Volunteers; people were coming as part of their ordinary school week, were they, too...

Yeah, yeah. I mean they were given an afternoon. And I think it was excellent. I wish they did it today because I think it's an excellent way of people meeting people with different difficulties, and it certainly gave a lot of people a lot of pleasure. OK perhaps some of them, perhaps most of them, were elderly. But it gave people a sense of purpose. And I think it helped the schools as well because the children that were doing it, the students that were doing it, were seeing what it was like for people to have certain kinds of difficulty and were helping them to enjoy life. And it must be good when you get people mixing; it's got to be good. It's much better than sitting here waiting for the sky to fall in. It's so nice when people are on their own if somebody calls to see them and offers to take them out or do their groceries or take them for a walk in the park. They're only small things but they mean a lot when you can't do it yourself.

And this was what, typically a weekly visit?

Yes, yes. I mean they might only do it for a term or so and then another group would possibly do it, or they might do it for a whole year. I don't think the whole school did it very much, because I think it was basically the older ones. But it was certainly a wonderful way of bridging the gap, particularly for someone like myself who hadn't met that many able-bodied people. I mean when I came home the Methodist minister came to see me and he found me two able-bodied girls, one of which I'm still in touch

with today, who came to see me. And we used to go out. We used to think nothing of it. Eventually. It took about six months to persuade them that they could cope with pushing the chair – well, perhaps less than six months. It took a little while to persuade them to take me out and about, cos they'd never done it before. But once they'd done it we sort of went places together and did things together which is much more in common with everybody else. I mean, OK we didn't go and get rip roaring drunk or anything like that, but we went out to the youth club and coffee bars and met each other and went round to each other. That way we weren't only getting it across to the person who was helping us, but we were also getting it across to their families as well. So their family attitude changed. Because I think is what a lot of fears about disability is, because they don't understand that we're just the same as they are and sometimes it takes a lot of breaking down to get rid of all those fears. In fact sometimes you never do.

*So you were using a particular kind of wheelchair were you, for mobility at the time?
How would you describe your wheelchair, you know, at the time?*

Wheelchairs were just straight up and straight, with wheels on, straight up, a straight seat, canvas generally, and you had to keep an eye on them because once they started splitting they'd go. And I remember being up town one day and one of my canvases started to split, and we just got home and it was hanging by the last thread. We'd come in the back door, turned the corner and the last thread broke. And I nearly went down the drain hole. But they weren't comfortable, they weren't as comfortable but then, because we were younger, although by now I wasn't wearing callipers now – I gave them up, they were just too much – I suppose when you're younger you don't have the aches and pains that you do older, so you tend to put up with things far more. And also there wasn't the aerodynamics or the comfortable cushions that you can get today. There wasn't any thought given to posture, which a lot of thought is given to posture these days – how you sit in your wheelchair, whether you're comfortable in it, whether it's comfortable to you, whether it's doing any damage anywhere – none of that was even thought about, which I think is why some people with cerebral palsy now have problems because, you know, had it have been thought about we might have been in a bit better nick. [Laughs.] I mean I'm not being funny but, you know, I get aches and pains now and I think, 'Oh goodness,' you know, and which I didn't get

10 or 15 years ago. But I'm fairly philosophical; it's part of the ageing process and some of it is, but some of it is because we had to wear callipers and had to sit in odd positions and do odd things, which were not good, I don't think.

And in terms of, you know, going up into town, into Wellingborough with your two new friends; what kind of reaction did you get from people?

If people really didn't want to know they'd either stare and look away, walk on the other side of the road, or just blank you out totally. I have learnt over the years, particularly since I had helped when mum started not to be able to lift me, I had more and more help, I found the best thing is to smile at all people. A smile is a great bridge towards making people feel more comfortable. And also I said hello to people. But there's still an awful lot of people out there who don't learn. And this is why it's so important to get any good messages across about disability – all the positive messages about disability. I mean we know there's negative messages but, I mean, when I give talks to people at...

[End of Tape 5 Side A]

Tape 5 Side B [Track 9]

Does it matter? I won't be embarrassed whatever you say.

Sorry can you go from when we give talks again?

Yeah.

If you go from when we give talks to young people. I think that was when the tape -

Yeah, yeah.

So, yeah.

Yeah, yeah. Because I want people to ask me things and above all I want people to ask me what I feel about things. What I feel about not ever having been married, what I feel about not ever having a job, what I feel about boyfriends, if I've had any, which I have. Because I'm just the same as anybody else. The fact that I can't do certain things doesn't mean to say that I am immune from everything around me; it just means that I have to look at things slightly different. I have to be a lot more aware of people's difficulties with me.

What is your technique, you know, you're spreading understanding through the talks you give and particularly to young people. But in the street, if you like, if you get a negative reaction from strangers, perhaps staring, what is your reaction to that then?

I try very, very hard not to lose patience with anybody because it doesn't help, it just makes them more wary, whereas really you want them to have a better understanding, not a worse understanding of what disability is. Unfortunately not everybody sees it like that and so you're always going to get a small few that don't want to know, that don't understand, that can't understand and that won't understand. And I think the won't is the big bit cos if you want to understand, a bit of patience will sort everybody out. But unfortunately there is never enough time, so I generally make people laugh and talk about my experiences and funny things that have happened to me. Cos loads

of funny things have happened to me over the years and I think that helps people to realise that I'm human and once you can get through to an association, to somebody, like it be, 'Oh you use a computer – so do I'. 'Oh'. You know, once you say, 'Oh I've been swimming,' or 'Oh, I can do that,' or, 'Oh, have you heard this, it's nice', and they begin to see you as a real person and they too forget that you're disabled, it all sort of merges; you are disabled and they know you're disabled but they stop thinking about it 100 percent of the time and that is what is good, because then you can progress on to the more serious things. Then you can help them with whatever difficulties they have – not just difficulties with disabilities but difficulties with everything. You can become their confidante if you like or whatever they... And I think the main thing is to remember not to lose your cool. I mean I've got a very good friend who uses the word handicapped all the time. I can't make him stop his language. I mean I'm not going to win that one, I know I'm not. So, every time he says handicapped I say disabled because he might just get there in the end. The language has changed, you know. And, I mean, a lot of people who were brought up in languages years ago, in the language that was current. I mean when, back in the fifties people were still using – and in the sixties and in the seventies – people were still using the word cripple. People were still talking about bath chairs instead of wheelchairs. I mean some people don't even know Scope exists. They still talk of the Spastics Society. But you just have to gently correct. You can't force it down them. It's not the language they learnt. And this is what I sometimes deplore, in a way. I do believe in being reasonably politically correct in case I offend somebody, but at the same time I do think that... I've been involved in work with Social Services on committees and things for a long time, and I have never known so many changes of languages. And really I don't always think it's necessary. And we now use this – I think use is [a] horrible word. It doesn't do anything for me whatsoever. It makes me think of a used stamp stuck on an envelope; a used bit of paper. You know, as if you're no good. But it was something that came back because people with learning difficulties couldn't cope with bigger words or longer words. And now being a 'user' has become the word. And I think to myself, able-bodied people wouldn't want to be called users. You are a user of society, yes. But it is so devoid of anything. I'd much rather be a 'client', or even a 'patient'.

And so just to return to the history of Phab – of course standing originally for Physically Handicapped and Able-Bodied then – that was an organisation that was existing when you left school; tell me then more about your first contact with Phab.

Well it was. The first course was held in, well I went to the one in Northamptonshire; it was the first one they'd held. It was run by Northamptonshire Association of Youth Clubs. They found all the people to go on it.

So this was a course as opposed to a weekly meeting?

It was a course. What happens generally on these courses, and it still happens today, you do art, music, drama photography, dance, you do a variety of things, normally about four different courses which have tutors; and you do them in the morning and then in the afternoon you go somewhere. In the case of Northamptonshire we went out and about and in the case of Northamptonshire we went round villages asking villagers questions. You know, finding out about the village, the history of the place and things like that, which was very good because it got us into contact with people. On some of the Phab courses, particularly some of the early ones, we used to go out to tea. We didn't go out to tea to the one in Northamptonshire but plenty of people came to see us because it was a new and unique thing. And we were halfway through the course; it was a lovely summer's weather the first course I went on, it was beautiful weather, at a place called Grendon Hall which was the county youth residential centre. And it used to be a house. I'd been there when it was private and they held their own gymkhanas cos it's only a few miles out of Wellingborough. It's a lovely setting. And on a course you get the person that's leading the course, you get a nurse on the course in case anybody's ill or whatever, you get various tutors who are going to tutor the workshop, and you get able-bodied people and disabled people. You get female as well as male, and you get entertainment in the evening and you get all the meals provided. If you're going, and you go out somewhere. I mean 'out-out' away from, a ride, you know what I mean. And you get transported in some sort of vehicles when you're on the course, if you've got to go out anywhere.

So this first course you were on then, it was in the summer after you left school at Christmas?

Yeah.

And the hall itself then, that was in Northamptonshire?

No, the hall itself is five miles from Wellingborough in beautiful countryside in a little village called Grendon, and it is called Grendon Hall. It's again an old house, but it had a very wide staircase so people could carry the chairs upstairs; four people, one on each corner of the wheelchair, just grab a chair and take it upstairs because the stairway was wide enough to do that. So we didn't have to have bedrooms downstairs, we did go upstairs to bed. And it was a wonderful place because it had got atmosphere, beautiful atmosphere, it was in lovely surrounding countryside, and they'd actually got a swimming pool but they hadn't got that the very first time I went, they had it put in afterwards, and it was such a nice adventure to be looked after by people that had never done it before, who were more or less the same age as myself. And they would tell you everything about what they did at youth clubs and things like that, and we all got on so well it was incredible. I mean it must have been wanting to have happened because everybody got on so well. And everybody was saying well if able-bodied people can have youth clubs, and if we can do Phab, why can't we have a Phab youth club, cos they weren't called Phab in them days, they were called Treasure Troves. And it was partly because of National Association of Youth Clubs, who had done courses before the one at Northamptonshire. A group of people were elected to National Youth Council – National Association of Youth Clubs – and one of them happened to be a disabled man who had little arms, called Frank. And they had to have a project every year. They had to suggest to National Association of Youth Clubs what they felt was needed. And one year they came up with a course or a week activities which disabled people could participate equally with able-bodied people. And it was taken on board and it grew. And when we were about the second or third Phab course I think, possibly even later than that (cos they did one at their own country house Avon Tyrrell) then they decided to spread it a bit and Northamptonshire Direct, Northamptonshire Association of Youth Clubs the Reverend Harry Whittaker, he got to know about it and he was invited down to see the one at Avon Tyrrell. And he decided that he would put one on and that was the first one at Grendon.

So this was the first or this was amongst the first Phab week-long courses ever held?

Well no; there'd been one at Avon Tyrrell, there'd been one or two previous because there was an awful lot of planning to do, because of builders, because there weren't very many accessible buildings. We were very lucky at Grendon because it wasn't particularly big but we could use the upstairs because the upstairs was accessible due to the wide staircase which was cope-able if people carried a corner of a wheelchair each. And, you know, I mean they can only have so many because there only have so many in a room. There are only so many beds in a room anyway. But it was the most wonderful week in terms of learning about each other because you discovered that you weren't really that much different from anybody else. Even I can hold a paintbrush and paint a picture. It may not be the same sort of picture as what other people paint but I'm quite pleased with myself cos I do enjoy my painting and I can do things with painting. I can A: enjoy myself and B: usually get it to look something like decent, which gives me a degree of satisfaction, quite a lot of satisfaction cos, you know, it's good to be able to produce things and know you've done the best you can.

Describe to me, Dorcas, how you would hold or use a paintbrush.

Well we didn't know before we got there. They were a complete bunch of strangers like we were to them. I mean, OK yes I suppose in a way I did know some of the disabled because obviously most of them were local. Some of them were even from my school. But quite a lot of them I didn't know. And I certainly didn't know any of the able-bodied and not really any of the staff either.

So...

I mean OK in the beginning they used to have the Red Cross in to help bath people but they gave up quite soon because they suddenly realised that able-bodied people are just as capable as the Red Cross is; they know you and know how to help you. And we did music, drama, art and out and about. And the out and about was a bit extra because the out and about used to continue into the afternoon for those that hadn't done out and about, if you see what I mean. Reverend Harry Whittaker had

Mary Robinson there from National Association of Youth Clubs, and a lady called Lady Jean Mackenzie with whom I'm still friendly. And they were sort of there to give Harry moral support and physical support because they had run them before and knew, and had wanted to gauge how things were going and if things were going badly would step in and know what to do. I don't think anything did go badly actually, I can't recall anything. All I can recall a magnificently marvellous week. So much so that by the middle of the week we were thinking well we've got to continue our friendships with these people. Because they were from all over the place, they were from all over Northamptonshire, and we knew that if we didn't make the effort to try and get to say to somebody important, 'Look, can we have some sort of club? Can we have something where we can go on meeting because we need it. Because we've got nothing and they've got youth clubs.' And somehow or other I got bagged into chasing the leader round, trying to tell him this. And it was really hard because in actual fact I was leaving a day early because my parents were going on holiday, and this had all been a great time, I'd got one day left, well I was leaving the evening of the last night, and I had to chase like mad to pin Harry down and I pinned him down and I said, 'Please can we have something where we can all meet again. Let's not wait a whole year for something to happen again like this because,' I said, 'we're missing out'. And I said, 'We've all enjoyed ourselves so much. I'm not just saying this because I am me; I'm saying it and a collective group of people are saying please can we have something'. And he didn't promise anything but he didn't dismiss it out of hand. And eventually Phab developed Phab clubs. And our Phab club came [from] there, and that was where the word Phab came from because we had to call it something. It could be Treasure Trove. And Dennis, who was the Field Officer, not the Director cos Harry was the Director, he said 'I wore ...' He thought of the name and we all thought it was a very good idea cos it could be 'Fab' if it needed to be, you know. And because 'fab' in those days was quite a new 'in' expression, in other words 'fab' was cool [laughs], you know, it sort of stuck.

And so prior to that then, the organisation that was Phab was running these Treasure Trove clubs where they existed and they [were beginning these week-long courses. And was it then nationally that the Treasure Troves became Phab clubs all over?

Yes. I mean Phab grew in a, I mean, our Phab club was monthly to begin with. And it stayed like that for quite a long while and it took quite a bit of organising because we had to [get?] everybody to a point. And the point was Northampton because that was easiest for people to get to if they were coming from all parts of Northamptonshire. But I mean the Field Officer Dennis used to pack about six people in his car and pick them up en route and ferry them in, and goodness knows how many people they'd take home at night. And they'd get the Round Table, the Rotary and everybody else involved. And that was how we would have first started, then we had to get our own transport, which meant old ambulances because that way we could pack a few more wheelchairs in, and also we could take more people, but then we had to find drivers. And so, yeah there were allsorts of problems like that. But nationally it grew at an alarming rate, simply because it was what was needed. It was so much of a good idea to meet people and mix and to be able to do things for a week, and do things that possibly has meant that possible nearly all the people who were disabled had never done before.

And in the way that able-bodied people and disabled people of the same age met in Phab clubs, using as well partly the assistance of the able-bodied people, what was the philosophy? What was the atmosphere like of your particular Phab club?

The atmosphere; it was always more difficult on the first day because you've got to get to know people, but we always played some activity where they had to take a wheelchair. If it was folk dancing they had to grab a chair and do folk dancing with a wheelchair, so you pretty soon got mixed up. And if you can do that, if you can do something that involves both sets of people, then you hit the right notes straight away and people see what it's all about and they don't sit all the disabled people together on one side and all the able-bodied people in the other. It's very craftily stage-managed so that you sit together.

This was succeeding yearly summer courses, was this?

Yeah. And the courses are the same. You choose what you want to do – you can swap if you need to but, I mean, not many people do; possibly more do at Westminster because the courses are really good.

Is this the course -

You know, they might not choose the first course, they might not click with the subject or whatever, but on the whole it's just so amazing that people click so well. I've always been on the lookout for people that aren't enjoying themselves and I can generally spot a person a mile away and generally have some vague idea what the problem is as well. [Laughs.] But that's because I'm used to people.

The Westminster course [was] run with the help of students from Westminster School, I believe. And month to month then in your local Phab club, at your meetings, what were some of the sorts of things that people used to do?

Well we would always... The evening, the end of the week entertainment, which was usually the last full evening before you left.

This was on the course, on the weekly course?

Yeah.

Yeah.

And, and on all the weekly courses basically. And what you did, you did the entertainment from your workshop. In other words if you were in drama you put on some sort of play or something dramatic that involved both the able-bodied and the disabled and took it from there, and produced something. If you were in the art group you produced paintings and things which could be put up and shown, or you produced collages and things that could be put up and shown, or you'd paint scenery for the drama people that is equally put up and shown. If you're working in clay you make things. If you're working in video you do a video of what... Westminster has got it slightly different because they tend to work to a theme – music, drama and art and dance tend to work to one theme, but do their own thing within the theme.

Video of course would have come later, but between courses month to month, you know, through the rest of the summer, through the winter and so on, what were some of the things you used to do when you used to meet each month?

Well, keep in touch with people as much As possible, I think. Certainly I've never been a great telephoner, and since I don't do some of the Phab courses now because I'm really far too old [laughs]...

No...

... but I do do Westminster.

... I'm thinking of the early days, you know, in Wellingborough and Northampton. I'm just trying to get a picture of the early days of your Phab meetings, of what you did then.

Phab meetings were superb. They were always organised. We always had tea and coffee or coffee bar, which meant we could get a drink when we got there and we'd get a drink midway. We always had some form of speaker. We had time to talk amongst ourselves, but we always had some kind of speaker because there's all sorts of interesting things out there: we've had people that are model aircraft people, we've had people talk about local history, we've had people talk about people in prison, we've had people talk about opportunities for young people – anything and everything. We've had people talk about cats, dogs, paving stones, doing paintings, as wide a subject as you can get speakers about, we've had them.

And in the early days again, some of the activities; what kinds of things did you do just socially as it were?

Yeah, we sort of, well we had an art evening where we splashed paints around, we had an evening where a person would come and talk to us and involve us in his talk, we'd have quizzes and we'd have parties like anybody else, we'd always have a Christmas party which went fairly well. I suppose really there were only sort of 11 meetings done because we didn't have a meeting the month of the course. At least I

don't think we did. But then we gradually got to the point where we met fortnightly, and later on met weekly, but that took time. And again even when we were meeting weekly we'd have speakers and things, and things to do even if it was homemade entertainment. Because I found a lot of disabled people had missed out on so much that having a speaker was really interesting. You know, much better than just sitting there, because some people don't communicate and it's very difficult if they don't communicate if they're just going to sit there and not talk to anybody. You've got to be able to talk to people to find out what they like and what they dislike. And we had a committee and we were properly organised and we'd have a committee meeting every so often to plan things and to see if we were doing the right thing or the wrong thing. We'd fund raise a lot because we had to buy old ambulances and we'd even bought newer ones but most of them were either test driven, which tend to be a bit...

[End of Track 9]

Tape 6 Side A [Track 10]

I don't think Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] differs [to] an ordinary youth club, but I do think they are more structured in the sense that they are possibly more planned. They're not all about pop music, they're not all about parties, they're not all about sport, they're about a lot of different things. We would go swimming, we would go sightseeing, we did go out and about, you know. They were more about encouraging a person to see what was around them, particularly as not everybody had seen what was around them or could easily see what was around them. I mean, some of the parents went to work [parents of disabled people] so they didn't go out very much, and quite a lot of disabled people, certainly at the start of Phab, were very vehicle-less. You know, you're not talking about a vehicle being a major accessory; it wasn't heard of in quite the same way that it is today. I mean most people have got a car, some people have got two.

What was the year when you went on your first Phab course?

Absolutely hectic.

So what [was] the year?

Year?

Yeah, yeah.

Well I came home at Christmas '64 – no, '63 – so it would be '64.

It was the summer of '64. And, so obviously that was, you know, the beginning of a changing time, socially. What sort of numbers were (in the early days again) involved your particular Phab club then? What kinds of numbers of people?

A lot of wheelchair people, but also some quite disabled people with speech difficulties because they had nowhere to go. The original idea behind Phab was that

Phab was going to be a bridge in between the able-bodied world. In other words you were going to come to Phab, find out what you enjoyed, and go and do what you enjoyed. It never really hit that for a lot of people because a lot of people still came because they still needed Phab because there wasn't as much support anywhere else, and they couldn't jump that last little bit of the bridge. I would have loved people to have jumped the bridge because I think it would have given outside organisations just what they needed to accept disabled people. I mean, the guides and scouts have always accepted disabled people as I said before. But some of the other organisations were very slow to acknowledge that we could do anything with them, and were very unsure about taking on anybody disabled. So really, in some ways, Phab hasn't done all it should have done to promote outside organisations but then you can't suddenly cut people's enjoyment off because that would have been awful, that would have put them back about 10 paces. You know, and you can't do that to people because once they've all had freedom they want freedom and they want that freedom to continue because that freedom is important to their quality of life and their well-being. And you can't just suddenly turn round and say to them, 'Well you're able, you've been to Phab now, you can go to any organisation you wish to,' because, although that might be what's needed, it isn't what effectively happens because of the transport or because of their innermost fears. I mean...

So was the idea...

... people still have very real fears about going somewhere unknown. I mean one or two of the most obvious things that happened was when we visited other youth clubs. They were absolutely petrified, some of them, sometimes, you know, because they hadn't met any disabled people en bloc before and they couldn't understand how the able-bodied understood us. So you'd go somewhere and there'd be all our lot enjoying themselves, and the others would stand on the touchline waiting to sort of be involved. And that happened once or twice – [it] didn't happen very often cos most of the time when we went we went to something where everybody would eventually get mixed up anyway – but occasionally it backfired on us and we'd get people being really out of place because they just couldn't cope with A: seeing that many disabled and B: they just couldn't get their heads round it.

The original idea that, you know, Phab would function as an enabling organisation, enabling people to sample things, if you like, and then go on in perhaps non-disabled context to take others things up; but you found, did you, that only a few young people then had had actual face to face contact with disabled people?

Yeah. I think, you see, when you have a disability where you are fairly able but you are still disabled, the possibilities of going other places are much wider because you can get yourself there. That doesn't always apply. But when you've got somebody with a multiple disability, a multiple handicap, or cp [cerebral palsy] with something else, who can't talk to you, whose only way of showing you that he can enjoy himself is by his eyes and I've come across that, and I've come across how much he enjoyed himself – I could always tell. Only had to look into his eyes and I knew. And it is so important. That is where Phab is important because it virtually becomes the only place that they can go because they know that they're going to be accepted, and they know they're going to get the right sort of support. And with that level of support there is also a vast amount of support in the background from family and that, and family have to be confident that their offspring is going to be looked after, and not going to end up in a state.

And being involved as you were in the running of Phab locally and taking such an active part in Phab yourself, aged 17, 18, 19; how did this then change your outlook?

I grew much more aware about other people's feelings. I think I'd always been aware, but I certainly learnt an awful lot about people and I discovered that, because I was enjoying it so much myself, it meant so much to me to make other people enjoy it as well. And so it was twofold: I was getting a great kick out of doing it and I was trying hard to make it more possible for more people to enjoy it, for more people to go on it, for more people to be accepted, and it gives you a kind of insight into nothing you can believe. I mean, it also brings problems. People had tremendous problems. Problems of not getting on with parents, not being able to reconcile themselves to the fact that they're disabled, not being able to reconcile the fact that they haven't got a boyfriend, not to be able to reconcile themselves to the fact that they're not going to have a job because that's too complicated and the world can't support two people let alone support one and all these kinds of things. You get them all thrown at you at the same

time because they're all living problems. And they were big problems in those days and I decided that, rather than get stressed up because I couldn't have a job, I would do things that were possible. And because I made that decision quite a long time ago and I stuck to it, it's brought me riches beyond belief, it really has. OK it's brought problems as well because I've always been the sort of person that's done things first, [laughs] you know, like care. You know, that's brought problems as well. But you have to, because it puts everything in its proper perspective and I do not regret at all being disabled.

What led you to the belief then that, after you'd left school and in the early years following leaving school, a job of whatever kind wasn't something that you would be tackling?

Oh gosh that's an enormous question.

Who was telling you really that a job wasn't for you?

I don't know really; I think I came to the conclusion that I'd seen other people get so miserable and so unhappy that I wasn't going to go down that path. Somewhere I have innate wisdom. [Laughs.] I don't know where, but it seems to come to my aid quite a lot. It seemed to be telling me the right way to go. I mean, I didn't get confirmed until about 30 years ago. It took me a long time cos I was looking for a church that would come to me as well as me go to it, and a lot of churches weren't doing that. And I worked hard and I found a very good vicar who understood where I was coming from cos he had a wife who'd been in a wheelchair. She was only temporary disabled but she died in the end cos she'd got cancer, but he knew where I was coming from. And I think if you get people to encourage you, you know, you're on the right track. It's when you don't have anybody to encourage you and you don't get anywhere that you begin to feel, well am I doing the right thing? And because I need so much help, like being dressed, fed and what have you, I'm very realistic about society and I would far rather be realistic than live in cloud cuckoo land hoping for something that isn't going to come my way. I don't say 'isn't' but 'hasn't' come my way, let's put it, and if I say 'hasn't' that's better than 'isn't' because 'hasn't' means that it still might come my way, whereas 'isn't' it's a bit too final.

And were you given, you know, the option of discussing with anybody or any organisation any kind of work options at all?

No. I've done CSV [Community Service Volunteers] for a whole year and been paid for that. The money went on an access guide for Wellingborough.

We'll perhaps come to that separately, but...

I worked with [them] back in the eighties. I've done various bits and pieces for all sorts of organisations but it's no good being voluntary. I have had very little paid work but I do do it when I can, providing it doesn't interfere with my benefits, but I do do it. Unfortunately the paid work that I'm offered is never enough to cover my expenses for my care for me to come off benefit. So it's a bit of a chicken and egg situation. I couldn't do it full time because it wouldn't pay for my care and I need my care in order to do what I do.

But in the early days when you were, you know, living back at home...

And, well, in the early days I think it was harder for me to accept.

... was it ever discussed?

But I think you do, because I was busy. Yeah, I keep myself reasonably, fairly busy. I don't very often have much free time and because of that I'm not bored. And because I don't really know what boredom is, if I'm bored I read. Well, I'm not bored, but if I've got spare time I read. If I've got spare time I read the newspaper, read a book, you know.

Was it ever discussed with you, you know, as to whether you might want to explore any options that were then possibly available at all?

I don't think it was ever mooted. Because I think by the time possibilities might have happened it was too late anyway. You know, I mean I'm 58 now, I've certainly had a

great yearning over the last 15 years to do something, but to do what and with whom I haven't got a clue because nothing's come up.

So how did you feel, you know, when you entered your twenties and you're busy still with Phab?

I must admit I felt quite optimistic. I had one or two experiences with men, one which left me a bit devastated but I coped, I just eventually coped with it. You do, you have to. You can't hang on to things what might have been – if you hang on to them too long they take over. You've got to let things go and start again or do something or come to sort of reconciliation point. I would never hurt anybody. If they hurt me yes, they hurt me, but I try not to hurt them back. It's very difficult to do sometimes but my belief is such that disability is not here to hurt people, disability is here to provide understandings between people. And if I can make people understand and if I can avoid conflict and I can avoid hurt – not always totally, because I'm a person like anybody else and I get cross about things – but I've learnt that it's far better to stay calm and practical than it is to go and get on a high horse and scream your head off.

So was Phab then, in your twenties and so on, the main way in which you met other people?

Yeah. I mean, because I've always been an outward sort of person – outward in mixing with people and things like that – things were nowhere near as bad as they could have been, and certainly nowhere near as bad as trying to find somebody that last year at school. Nothing could ever be as bad as that again. Well yes, I suppose it could; I mean this last year's been hard because of lack of care. But lack of carers rather than lack of care. But, you know, nothing has ever seemed so devastatingly low because my parents didn't like me to get upset either, which I suppose is another inborn thing. If you're told that if, you know, somebody doesn't like you to get upset you don't get upset. You cope with it in another way and I suppose my way of coping with it was going out to Phab, to camps wherever I went and having a good time, which put everything back in the right perspective again. And I mean that is what I say when I say I've been incredibly lucky.

And in terms of opportunity to form close friendships, Phab was the main way that you met people was it?

I've got friends all over everywhere. I still find, well, I find that people tend to come to me rather than me go to people because I still think people have a fear about wheelchairs in their houses and things like that. I think that still exists but it doesn't for some people but it's just practicalities sometimes. I mean it's not always easy to go places and certainly as I've got bigger, in other words as I've got more solid, it's got harder to go to places and do things and that sort of thing, but I've got one or two friends in Wellingborough who ask me to their houses, and that always gives me a great deal of pleasure. I always love going out, love seeing people, and, I mean, when I go up town I always talk to people because I think that's essential as well.

So in addition to being involved in Phab you went, did you, on camping trips?

Well, camping came with Phab as well because I was involved with camping cos of Guiding and I went camping in 1960 before I actually left school and I'm still going to the same camp! [Laughs.] I'm going again in August. I shall have gone now thirty-ish... 43 years now.

Which camp is this, Dorcas?

It's Woodlarks at Farnham in Surrey. It was given by the Strover family, who lived on the outskirts of Farnham, [Martyn and Dorothea Strover and Christina Tisdall formed a charitable trust, each having donated an initial sum, and bought just 3 acres in 1930. As funds came in over the ensuing years, a series of further plots were added until in 1938 the land amounted to its present 12 acres] for a campsite with tents, not modern campsiting but with tents and a dormitory which holds about eight to a dozen. And it was given in the 1930s and it's wonderful. It holds weekly camps, which people can go to, from May to September every year. And they also have a workshop which is in the grounds but that is not do with camp, that is for physically disabled women and some men. It used to be women only but it does take men now who are disabled who make things, you know, to sell and that sort of thing. And they're just planning a two million pound re-vamp. It's got a heated swimming pool but the actual dormitories

first aid block, toilet, shelter have been there since the 1930s, [its] had bits added on, and they can't add any more on now because it's so old.

And so who is it run by?

It's run by Woodlarks Campsite Trust, and it's still in the same family. In other words the people that gave it have both died. He was in the First World War, Colonel Strovers was, and his wife. He died a long time before his wife but I met both of them, and then his daughter ran it and now his daughter is still nearby but the granddaughter's more involved, so it's passing down the... But they're a very involved family; it's still family orientated. They're a charity, they have a committee, they have all the, you know, they just let it out to people who are willing to organise a week, and our camp is one of the oldest camps that goes. And we - Pathfinders we are - have been known for about... It was one of the first camps to start up on a regular basis. That doesn't mean to say it started up in 1930s, it just means that it was one of the first camps to start on a regular basis. Some of the other camps that started up at that time have had to fold because, you know, all the members have gone. But we draw from all over the country so...

And so Pathfinders – that's a particular grouping, is it, that meets there?

Yeah it's just a name for the group that meets for one week a year. And we meet from people from all over everywhere. We take quite a lot of people from Manchester, which is a wonderful experience because they hadn't seen countryside, quite a lot of them, you know, and we give them an opportunity to do things that they've never done before. And it's very much like Phab except it's outdoors. It used to be a lot more Guide-orientated, you know, than it is now. We run it with anybody that wants to come and help.

Ideas similar to the Guiding movement, you mean?

Yeah. But, I mean, we used to recruit solely from the Guide movement but we don't anymore, we just recruit.

And so you've been there, have you, the same week typically?

Yeah. We have the same week every, well roughly around the same week every year. We've moved one week this year because we had a week last year where it was the result week of the A-levels and that affects our helpers so much and we were so short of help, and you really can't be that short of help. You know, there were people running around and it's hard work then. But it's wonderful because when I first went, back in the sixties, there was about nearly 50 of us and it was fab being outdoors and everybody encouraging everybody else. Slept in a tent, cooked sausages, cooked me own food over a fire, helped people, all a very broadening experience.

[End of Track 10]

Tape 6 Side B [Track 11]

When you came home from school, you know, you said that it was a rough time for you and that Phab and your other involvements changed your spirit of mind. In sort of acquiring the confidence to explain disability to others and to feel part of things, how long did that kind of confidence take to come to you?

It's never ending. It hasn't ended yet. Because I always find there's new things to learn about. I learnt a lot through Phab, I learnt a lot through camp, I learnt even more through travelling. I went on some world conferences which, although they cost a lot, were very effective at bringing back ideas, thoughts of how lucky we are to live in England when some people don't get anything, thoughts about disability, about why some people with some disabilities happen in some countries and why some countries they don't survive because there's not the medical attention, why the major disabilities carry things on their heads and other disabilities don't survive, how governments tackle the problem or don't tackle the problem, I mean some don't, people don't have any governmental help at all. You know, it's a vast learning experience and it just does not stop. It's like anything when you start. It's like an iceberg. You never know what you're going to learn. And, I mean, I am amazed at some of the things in this enlightened day and age, if it is enlightened day and age, are still not solved. I still have problems when I go into hospital because they don't know how to move me or they don't want to move me the way that I like being moved. And, you know, things like that, for me, can be a hindrance. And it's awfully hard work sometimes to get little things across to people.

And the conferences that you went to abroad; what was the organisation then that you were involved in, in travelling to these conferences?

Well I suppose really I'd become involved with Ability Northants, which was Council for the Disabled in Northamptonshire, and that's been a 20 year involvement. But before I was involved with that, Phab started going abroad so I started going abroad with Phab, which was a great experience. We had some wonderful times. We had some first class helpers. Admittedly the first Phab course abroad, the people were picked to go on it, and I can quite understand why they had to be because they really

didn't know how it was going to go, and we all went in an old ambulance and travelled around in it and went and got there and...

Where were you headed? Where did you go?

Paris, France. And we stayed at a boys' school out of Paris. Quite a long way out of Paris, which was reasonably accessible, it wasn't the best example. The gardens were superb and the chef was a wonderful man. He used to make profiteroles long before profiteroles were the favourite that they are now. And he used to fill them with fresh cream and he used to come round and pass them all around. He was fantastic! And, you know, so we did have quite nice food.

So, what year would this first trip to France, to Paris be, Dorcas, do you think?

Yes.

What year?

I don't know whether Paris was my first trip. It was certainly my first trip with Phab. I think ... yes it possibly was my first trip.

What year would that be, d'you reckon?

Well I'd been to Our Chalet which is the International Guides Chalet [International Guiding House, Adelboden, Switzerland] with the Guides. And then I took my own helpers. They chose the helpers that went and we went. And that was quite an experience cos we flew. No we didn't, we went by train. We didn't fly. Or did we fly? No, I think we flew. Yes, I'm sure we... yeah we did fly. But I had several helpers just for me because I knew it wasn't going to be that easy and that was quite an experience I remember.

So would this be late sixties sort of time, that you...?

Flights are quite easy as far as I'm concerned so long as I give them the right information. And I'm always very careful when I go to the travel agent to make sure that they know the right information. Because I know that several of my disabled friends have been on holiday and it hasn't been successful because sometimes they haven't enquired very closely enough about access and things like that, which you need to be. You need to make the travel agent aware of what you mean by access.

So when you went to France for the first time – let's imagine it to be what, would you think probably late 1960s? – what was the sort of attitude that you encountered, you know, in the street if you like? What reaction did you get from people?

A lot of negative reaction from the average French person in the street because I don't think they'd really seen disabled people, yes, but I don't think they'd ever seen disabled people thoroughly liberated and just thoroughly enjoying themselves! [Laughs.] And I must admit we were a very happy party on the whole; we went around quite happily. And I know we went round a roundabout the wrong way and the French policeman just threw up his hands in despair and said, 'Oh, you English', sort of thing! [Laughs.]

So you drove around and what things did you do on holiday? Visiting places?

We went to see Chartres Cathedral [Cathedral of Chartres], which is something that I have done more recently because I wanted to go back, because I have never forgotten the windows of Chartres Cathedral because they're mediaeval glass. And that is wonderful because there isn't a lot of mediaeval glass round here! [Laughs.] And I remembered the windows and I wanted to go back and I went back and it was worth every penny just to see those windows. We also went to Versailles, which I've also been back to, so you can tell they had great impact on me because they are one of the things that I had to go back and see. We went to the Eiffel Tower, which caused a riot because one the blokes kissed me underneath the Eiffel Tower and that was fun! And then at teatime he said I'd got a mouth like the Mersey tunnel, which caused another riot! Oh we did laugh! [Laughs.] I mean, it was just so good humoured.

Did you go up the Eiffel Tower at all?

Yeah I think we did, and I've been up it since. I mean, I love Paris. Paris to me is art. I've got a good friend who lives near Paris and I just like Paris. I really, really like Paris. I like Paris, I like Rome. I've had some wonderful times in Rome on with friends. But I just love Paris. I like lots. I like the churches La San Chapelle, behind Notre Dame. Notre Dame I find a bit disappointing cos it's always full of tourists who don't want to move out of your way and don't want you to see anything, and I find that very hard going.

So when did you first go to Rome?

Rome I went to because one of the boys that I got to know through dad became a priest. He was a particular friend of mine, a very good friend, and he did his training (his seminary training it would be) in Ireland, and I couldn't go and see him in Ireland but I went to Rome to see him, and I made lots of friends in Rome through him. And I went several times and I have some very fond memories of Rome. I've seen Rome walking; literally being pushed around Rome. A bit like Paris cos I've been pushed round Paris as well. And, and I still think it's the best way to see these places because you really do see them. I mean, you're on foot, you take your time, you get there and you look round and you observe. And one thing that Guiding always taught me was to observe so I really appreciate some of the places that I've seen.

And your early trip to Rome, going around via wheelchair; how did the wheelchair stand up to going around?

Not very well I must say. [Laughs.] There's loads of funny tales that I always share [inaud]. I needed a wheelchair to go to Rome because I had my wheelchair checked before I went and he said, 'Oh you can't take that chair, it's gone on a bit [got old]; it's got a crack in it. We'll supply you with one'. Well the one he supplied me with was so old it didn't stand up to the first day in Rome. Both wheels went square as we went off a pavement and caused a little policeman panic because he saw it happening and he thought it was like a Charlie Chaplin film, so did I because my wheels just clanged, both of them.

So they buckled?

Yeah buckled, yeah. But they went back but they were severely not right. So we went to my friend's from where we was lodging, and where his church was and we said we'd got to get a new wheelchair. So he took us out on the Appian Way out of Rome that evening to a hospital and this priest came out, took one look at me and said, 'Large Lady,' and disappeared and brought back a wheelchair that was even older, that wouldn't even fold up. So we had to tie that to the top of this little Fiat car, which made us twice as high, and we got back with it, untied it, got in with it. Next day we went to the Coliseum and the front wheel dropped off this chair and it rolled between the gutter and it rolled straight between the legs of a priest who had got a hat on and a long, long gown. It bounced on his gown into the [?]. I was the only one that was seeing it because all the helpers were talking. I was doubled up with laughter, I was absolutely nearly squeaking with laughter – it was quite funny. And, it was still rolling when I told them it was gone, the wheel. And they rushed after it. Then a little man came up with a bit of wire from his ice cream van, wanting to tie this wheel in with this bit of wire. Well we couldn't get it on so I had to cuddle this wheel all the way back to the other side of the Vatican. Cos I mean it was all right, it was only the front wheel, so long as somebody held the back I was perfectly safe; I wasn't going to fall out cos I mean it was just like pushing it with four wheels on except there was no wheel that side. So we got back with me cuddling the wheel, it was pouring with rain, so I sat in the shower room and bathroom and three hours later they still hadn't mended it. So we slung the spanner at it. No, we couldn't mend it. So we decided well what were we going to do? So we tied it on with a crepe bandage. And the next day I went to a papal audience with this bandage on. And I had to say a prayer every five seconds that the wheel wasn't going to drop off [interviewer speaks] because I was absolutely terrified that the wheel was going to drop off, either in the middle of [laughs] the service, which would have absolutely awful, or when we were moving along the Vatican you see.

So who was the current pope then, Dorcas?

Three popes ago, Pope John something or other.

John Paul?

Pope John the... No, before that, back in the early seventies.

And what was it like the...

Yeah. And...

.What was it like seeing the -

...the one before the one that only reigned a few short days.

Right. What was it [like] being in the presence of the then pope?

Oh it was wonderful. But I must finish telling you the story about what happened. The guard said, 'There's hundreds of seats for disabled people, afterwards, so I suggest you sit here and we'll move you at the right moment.' So I was sat there, which wasn't our seat number at all, but we were with other disabled people. And then afterwards we moved again. I said a quick prayer so that the wheel didn't fall off. And he came round and he looked straight at the bandage on the wheelchair, straight at me, and he said, 'How are you?' and 'Where are you from and how are you?' So I said England and then I said that I was fine. I mean I was. But he did give the bandage a queer look on my wheelchair. [Laughs.] So we had this problem and we got two more days through with this bandage on and we got really fed up with it. So I sat again in the bathroom, sat on there for three hours and Ken was just about pulling his hair out. That was the fella who come with us to help. He chucked the spanner at it. The spanner hit a bit of the chair, the nut that we'd been trying to get out all week dropped out and we were able to put it back together again. [Laughs.] But by this time, I'd got a ring of confidence round me bottom from sitting on the loo for too long! [Laughs.] Oh we had some wonderful moments, we really did, I mean the things that I've done on these, pumped over cobblestones at Pompeii and had all sorts of adventures. I mean I've had a wheelchair collapse in Paris as well when I went on a private visit, and we had to get help. That was quite strange as well cos we were going to Notre Dame that day and Little John's wife – John who's helping now – his wife,

before they were married, who I meet at camp, was picking up the spokes as she was going along and putting them in her pocket as they were falling out of the wheel! [Laughs.] So, I mean, these adventures are real... I mean, I make people laugh because I have had some tremendous adventures and they all add to joys of living.

And, you know, opportunities to go to different places, see different people and experience the world in that, in that way. So in undertaking the different trips with Phab and with other situations, you were as well getting further involved, were you, in disability issues as we would now describe them?

Yes because I found out in some of the countries, I found out in France and in Italy because I got to know some local people, particularly in Italy they said that the disabled there used to come out at nightfall, just have a quick hurry round and go back home again. You didn't see them very much in the daytime, in fact only until I used to go [in] my later years, did I actually see any disabled people other than tourists. I saw more disabled people in France because I actually went to Lourdes a number of times, which I also thoroughly enjoyed, but don't go now. Because I'm not a Roman Catholic. I'm not against [coughs] anything. I'm quite a free thinker where religion is concerned, and I did benefit greatly particularly 22 years ago when my dad died; I went to Lourdes the week he died, because I was already booked to go. And...

What was the atmosphere like at Lourdes?

Very wonderful, if you can get it. Some people found it far too commercialised. But I've been to lots of places and, yes, you cannot have that sort of situation without the commercialisation: it comes with it. I mean, the Holy Land where I had a most wonderful time with Phab, was very commercialised. And Lourdes is very commercialised. But there is still a wonderful sense. Hosanna House is not in Lourdes, it's out of Lourdes, and that's the most wonderful principled place in rural France that you could ever get. Also you go round a grotto, get away into one of the fields across the other side of the river, and you're far enough away just to hear the singing and not to hear all the... [inaud]... that goes on. But it is a most marvellous experience and I'll tell you why. It's a very humbling experience because you always see somebody who is much worse than you are and needs help. Well you don't just see

one person; you see lots of people like that. And you see lots of people who are very much in need of help. You see a lot of people who despair as well. But you also see a lot of people who give hope. And somehow all through the commercialisation, all through the despair, there is something there to give you an uplift. In fact I would say that every time I went, although I wasn't physically cured, I certainly felt better for going. I think it does something for your mental abilities as well. It really refreshes you. You know, I don't know what it is. It's not tangible, it just happens. And I don't know why it happens, I don't know whether it's because you're receptive to it and it just happens or whether it's prying about it or what it is. I've actually met somebody who was cured. I don't know whether I want to be cured. I have no desire to suddenly become able-bodied for some reason. I think I am satisfied enough with my life as it is not to really want to suddenly be able-bodied.

And so seemingly this person then gained sufficient strength from a visit to Lourdes to feel differently from what they were?

The first pilgrimage I did was exceptionally hard. Hard because all of them wanted to be cured and were terribly disappointed when they weren't. And I could have told them that they weren't necessarily going to get cured in that sort of way. I wasn't disappointed at all. I was just so grateful for the peace that it gave me. And, as I say, it's not anything that you can really put a finger on. It's just being there. I met a young man there and got very friendly with him, but he was so disabled, he so wanted to come and live in Wellingborough with me, and it just wasn't possible because I needed to have, he couldn't speak, I needed to talk for him as well as talk for myself, I needed to guide him everywhere. And really, my vicar, who I've previously mentioned, said, 'You'll take on too much. It'll become too much and it'll become a burden and you're better off without that burden.' And I think that is really why I've possibly not gone back. I could go back and go with a different group; I would like to go back sometime. But I don't think I could go back and feel as... I don't think I would feel comfortable because I don't want to be thinking about this person and I don't think that's fair.

And so as the years flowed by, one year followed another, what were your motivations, what kept your outlook as it was?

Being able to go away, being able to be with friends, being able to find new challenges, do new things, help more people, and eventually become a carer for mum as well because when her health started to go I was sort of keeping her going as well as keeping myself going. So life to me has always been one challenge after another, which I grasp when I can, and I've also been to some wonderful places, I mean I've done lots of things with RADAR [Royal Association for Disability and Rehabilitation], I've done world conferences with RADAR, I've done conferences with Mobility International, and, you know, there's been all sorts of things that have kept me going, for which I'm mightily grateful. And after Phab, of course, came my book writing.

RADAR (the Royal Association for Disability and Rehabilitation) and Mobility International then, how did your involvement there come about?

Well that was something I came across through RADAR and the world conferences. I met somebody who was Mobility International orientated and they got me involved in their things.

So what was the aim of the organisation?

To provide a place to go at a sort of semi-conference level, to go and visit and learn and enjoy as well. So part of it was receiving the information about that country, and part of it was giving, enjoying that country as well. So it was a bit like Phab only it was on a different scale. It was for a much more all-age concept. You know, they weren't all young people although the majority were young, but we had professional people come and give us talks about disability of that country, about what was being done in that country about all sorts of things. And that was good as well, that was that. But, although it still exists – I think it still exists – I haven't been on it for a number of years because it's expensive, and it's increasingly difficult to find helpers to go on these things.

So it was an international gathering, what, every year, was it, typically?

Yeah. No I think it was every other year. And whereas when I first started going they had a nucleus of helpers, gradually they've lost that nucleus of helpers so things have become more difficult, so you couldn't go unless you could have a helper because, you know, there had to be enough people to look after the group. But it was like a mini RADAR world conference in a sense. Only it used to target up one country at a time, where RADAR...

[End of Track 11]

Tape 7 Side A [Track 12]

So with Mobility International then, Dorcas, what were some of locations that you got to visit?

Well I visited several places. We had one in Edinburgh and then I progressed to RADAR and I did one in Portugal and one in Japan and one in America. The one in America was the first one that I did.

First RADAR one was it, yes?

Yeah. That was in Florida. Then the one in Portugal was Lisbon, which I thoroughly enjoyed, and then I did one in Japan, which was absolutely wonderful. Just the culture in Japan was entirely different, and in all of them I learnt a tremendous amount about other countries and how support was given in other countries to people with disabilities. I met all kinds of people. I met and conversed with people from India, one or two off the African continent, I met a young man who had no arm and when asked why he hadn't got an arm I was told, 'Oh a snake bit it.' And the quickest thing to do to get rid of the venom of the snake was cut the arm off, so they cut the arm off. And he went back to school, and because he hadn't got an arm he was not able to do his schoolwork but some relief agency, and I don't know what relief agency, got him a place where he could go to college. He went to college and he came back to England and talked to people at various conferences (which is where I came to know his story) and he was actually going home to Africa to start organising better lives for the disabled people out there because what people tend to forget is that the wheelchairs that we use here or the implements that help us here, don't necessarily help us in Africa because the problems are so different. I mean the roads aren't roads. You've just got a muddy track sometimes and a muddy track and a wheelchair don't get along together. Or you've just got sand to push your wheelchair along. So he was building things that could go better over sand or better over mud, which were not like the conventional wheelchair. And the same with crutches and arm supports and things like that. They all have to be sort of modified for the country to fit their... You just can't send a whole load of things from England and expect them to be suitable. Because once they're broken where are they going to get the parts from?

So your involvement with RADAR world conferences and Mobility International, that was, what, through part of the seventies and into the eighties was it?

Yeah.

And you talked about the culture being particularly different in Japan. Tell me a little bit more about that.

Well, I don't know what I... I didn't have any preconceived ideas. I think that's good anyway because I think if you have preconceived ideas you get a bit in a one fixed mind about those things. But very much more aware about disabilities than I thought they would be. They have a very simple way of coping with wheelchairs on buses – they just put blocks of wood under the wheels. And it's something that they put on the floor of the bus that the planks of wood have got something on so they grip and they're like chocks...

What about -

... under the wheels.

What about access to the buses themselves?

Access to the buses; if they're accessible they've got a little wheelchair symbol on and you just get on them. The drivers all wear white gloves but if you get on a bus that's got a wheelchair symbol they'll always make sure you're safe. I mean I was petrified when I arrived because they only just put these blocks under the wheels and you think you're going to move everywhere and you don't move at all, you know. I mean here we clamp everything down and strap everything on and, you know, and yet they just put simple blocks under the wheels and somehow they hold! And of course the buses are low wheel, low load-bearing buses [laughs] which means the floor's lower but, I mean, not all the buses are low floors but I saw so many with the disabled symbol on which means that a lot of people must travel on them.

And in going to different buses [countries], besides experiencing the different cultures and the different atmospheres of the countries, how did all this work that you were doing, how did that contribute then to your greater understanding of disability?

A lot. Because anything that widens your experience of disability is useful because I never know what I'm going to be asked tomorrow. And if you can explain to people the way that things happen in other countries and what is available in other countries and more what is not available in other countries they begin to get a better perspective on their own country. Which I think not everything's bad in this country, far from it. I mean, I know we moan about things but really we are very lucky to get any sort of pension whatsoever. I don't know what I'd do if I hadn't got any pension mind you. I do wonder about for some of the countries that put a, you know, how do people survive? I don't think a lot of people in the third world who are disabled do survive.

And in terms of your own sense of identity, perhaps when people are younger they have a particular attitude, do you feel that your own sense of identity perhaps as somebody with a disability, how has that changed over the years?

I've become calmer about things. I've had to because when you get a lot of people's problems you can take them on but you can't always solve them, and you've got to be able to turn them off. Because if you carry them round you end up like two girls that I was with at camp last year who were in tears for quite a lot of the time because of the baggage that they were carrying around about cretins, things that had happened. And this always bothers me slightly because I don't think enough attention is paid to the baggage that people do carry around when they have got problems. People need to be able to leave their baggage behind them if they can, but that is a very hard lesson to learn, but it's one that I've learnt because carrying baggage around means that they can't possibly fully enjoy themselves because they've always got a worry about something or other.

And when you say baggage, what kinds of issues tend to be raised that you would describe as baggage?

Parents not getting on, parents getting too protective, people saying horrible things and them not understanding why they're being said and not being able to tell anybody because they've got learning difficulties or because they can't really put it into words to anybody that they don't know. They come to a place where they can start enjoying themselves, they know they can talk, they talk but because they're only with you for a week or so, however many days it is, you can only cheer them up for that bit of the time. And you can't do much about it, which I think is a pity because I think in some ways they still need help when they go home – it all comes back again and nothing has been solved, except perhaps you listening to them. But you can't do anything with it because their home's miles away. But at least they've had a few good days respite from it even if it comes back when they get back home, or even if it comes back before they get back home, as I know in the cases that I had last year I know darn well it was back before they went home because they were dreading going home.

And in your own instance, Dorcas, your outlook, your attitude to life if you like, how did that perhaps change, or did it indeed change, you know, through your twenties into your thirties and as the years went by?

I've grown much more aware of people, much more aware of problems, much more aware that more needs to be done, more people need to be available at the grass roots to help people. And I think in some cases it should be disabled people that do it because disabled people are the only people that know what it's like to be disabled.

And so there you were then, living with your mother and father initially, then after a time your father died and so it was just then perhaps yourself and your mum. And you referred to the fact that you, in later years, became a carer of your mother. How did you feel about the fact that you were living - ?

The biggest fear of that was mother herself. Because she wanted me to go into a home, where she knew I would be protected. I knew that I would rather be anywhere else. But we'd always argue about it and I literally mean argue. She'd get really upset about that, so I would try and keep off the subject. But I knew. Luckily the vicar came to the rescue in the end because mum had to go in and I had to tour the country for 14 weeks with friends while she was in hospital. She wasn't allowed to lift me or

anything. And I went round the country and my vicar happened to come up to Ripon when I was in Harrogate and came to see me and he said, 'Look, she wants you to go into a home when anything happens to her.' I said, 'Well I can't.'

Was this suggested just whilst your mother was in hospital then, or as a more permanent...

Yeah.

... arrangement? Right.

Yeah. I said I can't go into a home when anything happens to her. I said I want to be free to be able to carry on helping people and doing what I can for people and being generally useful I said I don't want to go into a home and go back to the point where people are jealous of me because of what I've done and because I've sat there. I've been able to go here and there and everywhere. Because a lot of people were terribly jealous of me in Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] at one stage and it was really... A lot of it was unsaid – I mean unsaid from my point of view, not unsaid from their point of view, they made their point of view very plain.

In what ways? What gave people reason to be jealous, Dorcas?

Because I went on holiday, because I organised my own help to go on holiday, because I enjoyed myself, because I appeared to be able to do certain things that they wanted to do but weren't prepared to give the time to do them. You have to have time to do them. I mean, for that trip to Paris, the one where I took my own help, I wrote 300 letters to get help. I've done that many a... not so many as that but that is how I get help. You don't just sit at home and wait for help to come. It's slightly different now I've got care but you have to do something. If you want to go anywhere you don't sit on your backside and wait for it to happen. I mean, OK it did happen with Phab – and it still does happen with Phab in fact – but if I want to go anywhere it's up to me to make it possible for me to go, it's not up to anybody else. And they just couldn't understand that and it caused an awful disagreement and lot of jealousy. And

in the end I finished with doing the Northampton Phab and set my own Phab up in Kettering which was the same thing, only different.

And this, you know, writing around and contacting people, this was to also see if there was a possibility of getting assistance with funding for things like the whole Phab group?

Yeah. I mean, you know, you've got to do all these sorts of things and I think that was the hardest thing – overcoming people's jealousy. And I don't ever want to go back to that situation because it is so disastrous. It's negative, but not only is it negative it is absolutely disastrous because it turns everything good into something horrible somehow. And although I can cope with people being jealous of me I can't... I've got so much that I can do...

And you referred earlier to the...

... though it's unpaid. I know it's unpaid what I do, most of, but I've got so much that I can do and give that I really don't want to be coping with people being jealous. [Laughs.] It's something that, unless I have to, I don't do.

And you referred earlier to, you know, talking to school students and others about disability, about your own circumstances. When did you first begin that work?

Repeat the question again, Philip, please.

You referred earlier to going around to schools and talking to students...

I think it came with the knowledge that I was somebody that knew what I knew, knew what I was talking about basically, and it's grown. I mean because of the way that I do it, because I'm quite easy and quite approachable, it seems to work. And I think a lot of it is word of mouth.

So when did you first start doing that work?

I should think about 15 – 10 years after I left school. You know, it's grown and it's grown different over the years. I mean now it's much more about how I survived than it was years ago. But it's also about being disabled as well. Because I still find people don't fully... I've made a lot more people understand because I now do a thing called Desert Island Discs which is like Desert Island Discs. I play music and talk. And I do this now for a load of pensioners clubs and various under-pensioners clubs and various older groups, and it goes down really well because I think it brings it over to them that I know what I'm on about.

And what -

And I think you've got to be careful how you put disability over because you want it to be positive to them. And, you know, I think a lot of it was I was very lucky I had a father that could see my potential, I had a mother that would have helped anybody, which is part of me as well, and although I had a mother that worried, that thought that I was going to get put on, I have been put on a bit but I haven't been put on as much as she thought I was going to get put on, and I have survived that sort of experience. And I am very glad that I am still in society and that I will carry on doing and carry on trying to live in the way that I live now for as long as I can because to me it gives me everything I need as well as giving other people something as well.

And when you say you tell people how you survived, just expand on that a bit for me if you would?

How I think people find it very hard to understand the type of care I need. You know, because when they see me they see me fully dressed, they see me talking about things that I've done, some of which are things that they have never done, and I think they find it very hard to sometimes see that I need feeding and dressing and everything doing for me. And although I tell them that I am capable of telling people how to do it, they still need help to realise what it is I need help over. So, you know, I mean if you've never had any experience with anybody who is disabled you do not know what the needs are. And older people, as well as younger people, in fact almost any age person, if they've not had that experience, they cannot conceive what it is like. They cannot know what goes on, what is painful, and I don't mean pulling about painful,

but what is painful mentally, or what is painful physically, because their life is so different and sometimes they over-imagine the painful bits, because they imagine it's all painful and it's not, and sometimes they have no imagine [imagination?] at all [coughs] so they can't understand anything of it. And it's that which is so difficult to describe to people. It's people have no concept. And, and it's good in a way that there aren't more disabled people, but at the same time it's bad in a way that there aren't more disabled people because if there were more disabled people there would be more understanding. And the thing that I find very difficult is there are not that many people who are willing to talk about disabilities in a way that makes it positive. It's easy to talk about negative things because they're the things that happen to people and people get frustrated by negative things so they got to their MP and moan, or they go to somewhere and moan. But people don't feel very good about the positive things.

So what are, for yourself, the positive things you'd like to emphasise?

The positive things are making people feel comfortable with me so that they can tell me what they need to tell me and I can tell them what I need to tell them. And the positive things are going somewhere and enjoying oneself rather than, I mean going out in the rain the other Friday I enjoyed it, you know, because when I was younger I never went out in the rain because, 'Oh, that poor disabled person can't go out in the rain,' sort of thing. You know, and I defy odds like that because I am not a poor disabled person, I am a disabled person but I am not poor and I can certainly go out in the rain. I won't melt, I won't disappear. If I get a cold it's my own stupid fault for doing it. It isn't anybody else's responsibility. I am responsible for me. Nobody else is responsible for me. They all take on these mantles of responsibility and they all try to prove that they're responsible for me. Why can't I be responsible for me? I'm perfectly capable. You know, there's rules in society that able-bodied people love to think they're in control. But I'm in control of me, not anybody else. At least, sometimes they might be when they're pushing me or when they're doing something for me, but I'm in control of me most of the time. And, these are the things that matter, these are the things, and we are such a minority group and there are so few of us willing to say. I go to meetings and I go to meetings and meetings and meetings. Sometimes, if I've had a particularly run of bad meetings where it isn't always the organiser's fault that they're bad meetings, you know, they're just meetings where

you're not getting anywhere, I think: 'What the heck am I doing? What am I doing, why am I at this meeting trying to get things right, when nobody really wants to know?' I go home and I think, 'Oh, should I chuck it all in?' and then I go to bed and wake up the next morning, I think, 'No of course I shouldn't chuck it in; somebody's needed,' you know. So overnight a sleep on it is sometimes a very good thing. Sometimes when things have gone badly wrong I do wonder and I frequently get told off for doing too much.

And in the later years of your mother's life when in some senses, as you describe it, you became as well your mother's carer; what were the practical ways in which that became evident?

I used to get the bills paid, although when direct debit came in she went on to that which was a great help. But I used to have to organise things with my helpers so that we did bits of things for her as well. I mean I think, as I've said, the biggest problem was that she wanted me to go into a home, she couldn't see that I could survive like I have done since she's been gone. I must admit I miss both my parents dreadfully but I don't get in a morbid state about it because they gave me so much that I suppose in a way it's me wanting to give as much back as they gave me: as much understanding as they gave me, as much love as they gave me, as much giving as they gave me. All the things that they were good at I see a need to be good at as well. And I think that is the best epitaph that I could give them because I'm sure that is the way forward, that is not looking back and regretting things cos you can regret things and regret things and regret things but it doesn't change it. The best policy in life is live a day at a time, if you can, and enjoy that day to the full whether it be a good day or a horrible day. But enjoy it as much as you are able to and think positive of it and then the day doesn't seem such a trial even if it is a bad day.

[End of Track 12]

Tape 8 Side A [Track 13]

Here we are then, Dorcas. It's the 6th of July 2005, and I thought perhaps we'd start today with your involvement in different disability-related groups locally. What has been your involvement?

I've been involved with lots of things. I've always seen the need to get involved because I think it's one way that you can prove that you're a person in your own right. And I think it does other people good to see that one can get involved and do things for people. And I suppose one of the earliest things I got involved with, although I left it for a time, was Sequel [The Sequel Trust – Specialised Equipment Aids for Living]. Sequel came about because when we were at school at Delarue, one of the people that came to visit us to show us equipment was Roger [inaud] who was one of the founder members of Possum, which was a system by which disabled people could communicate. And I tried to get a Possum system but they wouldn't cough up the money so I had various business equipment. Because out of the Possum Association, which was founded when Possum became one of the 'in' pieces of equipment, came the Possum Users Association, and out of the Possum Users Association came the Sequel Trust. And the Sequel Trust is what provides communication aids for disabled people. And I belonged to it back in the late sixties, but I was the last member. I was a member and then I let it drop. And then, when I became involved in computers, my friend from London – Peter, who knew about Sequel – said, 'Why don't you get back in touch with Sequel?' And I did and I've been involved ever since. I'm now one of the trustees of Sequel. And it's brilliant. All the trustees are disabled, which I think is wonderful. When I say are disabled I mean we all have a physical difficulty of some description or another. And I think one of the nicest things about it is that we all get along so well. We meet three times a year. The only people that are able-bodied are the treasurers, the financial adviser, the sort of administrator and the administrator's deputy and the office lady. And we've manage to provide 90 pieces of equipment in a year, which means anything from a straight-forward computer to a page-turner, to a complicated equipment with all sorts of specialised adaptations in it, for people that can't use a computer in the more conventional way, which sometimes can cost up to five or six thousand. We ask people to fund-raise and then after they've been on the list... we put the rest of the money. And, you know, I think that the problem with it is

now that we have got quite a lot of people with quite a lot of equipment, and sometimes it all wears out at the same time, and because technology's moving so fast, they all want updates and so we've had to say now that we'll set aside so much money for repairs and updates because, you know, where we can repair we do and also where we can give tuition on reading the computer we do. And we don't supply as much as we have done at the heights because there's other organisations that do supply things and, you know, getting money is getting increasingly more difficult. But I think we do a very good job considering we're only a small charity and the fact that we only meet three times a year.

And, so Sequal – how are you spelling that?

Well, it's merely letting, our motto is letting lively minds go free. No; setting lively minds free. And what it is is helping people to communicate who have no communication. And it's not just communication for people who are... and that sort of thing, for some people it's virtually their only means of talking. And that's where it becomes very important.

Sequal then spelt S-E-Q-U-A-L?

Yeah.

Standing for Special Equipment and Aids for Living. And that's one of the groups that you've been involved in with other disabled people. What are some of the other groups that you've been involved in as well then, Dorcas?

Well, I'm involved with Ability Northampton Council for the Disabled, but we didn't like the 'for' bit, and we spent a long time trying to convince people that we needed to change our name. We were out-voted at one point so we had to keep the old name for another year. And that's an umbrella organisation and I'm a trustee of that as well, and at the moment we meet every month but sometimes we met every six weeks, and we provide information for people with a disability and we also do access for buildings and anything really that needs access to, advising people about the access

for the DDA [Disability Discrimination Act] and things like that. We will, well quite a lot of us will... and we can do it a lot cheaper than some of these architects can,

DDA -

... and people tend to come to us and we give our expert opinion and because we are disabled, quite a number of us are disabled, it means that we know what the problems are. Whereas architects don't always know what the problems are. They know what the DDA is, probably, but they don't necessarily know what it's like when you can't get in a building. And it's not just about getting in and out of buildings. When a building's in use it is very different from an empty building and people tend to shove things in aisles and things get in the way and, you know, I've had to deal with a query about some woman who couldn't get in to a charity shop because they'd got so much stuff packed in, she couldn't get round in her chair. And it's generally because the charity shops are so small.

DDA of course, Disability Discrimination Act. And so in the sequence of things then, we've had you involved in Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community] in particular, and locally, and other involvements, but when did you first come to be involved in groups that were aiming to achieve change?

I did my Duke of Edinburgh's Award, but before I did that I was involved with the Wellingborough Youth Council when I first came home from school. And luckily they accepted me. I think possibly because I went with a friend and the friend was also involved, and that helped tremendously to get me into it. And I did lots of inter-school work, which was called CSV – Community Service Volunteers – but it wasn't the CSV, it was in lots of secondary schools in Wellingborough, and they used to be able to go out and visit people and do things for them. And that was most important because when I moved to the do Dukes of Edinburgh's award, because of my age I entered at bronze level but took direct entry to gold, so I didn't actually get my silver and bronze, I just did them, but didn't get them if you see what I mean cos you do direct entry, cos that way is quicker.

So let's just pin this down to a particular date then, when you started work on the Duke of Edinburgh.

Well, yeah, I think you had to finish it when you were in your early twenties, you know.

And so how old would you be when you started Duke of Edinburgh work?

Sixteen? 17? 18? No, not 16. Seventeen, 18, if not older. So I hadn't got that long. But I enjoyed every moment of it because that again brought me in touch with a similar group of people, in fact some of the same people that I'd met through the school contacts. And I had great fun. I learnt about how you put fires out, how to rescue somebody from a burning building, just by giving them instructions on how to do it. I did a police course; I looked at the police cells. I did things like flower arranging where I told the person where to put the flowers. I did beauty and makeup which have never meant a great deal... [Laughs.] I mean, I don't wear make-up, I never have cos I always think it's one more thing for somebody to do. And I think, very often it's so easy to get plastered in makeup and it really does spoil your skin sometimes as well, particularly if you overdo it. And I've never felt any great need to do it. But I did the beauty and makeup course and that was quite interesting. I went to one of the Phab courses at Brendon for one of my... and I went to camp for another one, and I went to Paris for another one. That's my adventures.

So in terms of, you know, beginning work on the Duke of Edinburgh Award scheme at the time, were there many other disabled people that you were aware of, taking [part]?

I think I was one of the first disabled in the [scheme?]. I think one or two people had, but they were, I mean, the disabled were still referred to London and the people in London had the dealings with it. My friend – Mr [?] – who's died a few years ago but his wife's still alive, they were wonderful. I mean they came up to see me and they just had a way of dealing with disabled people which was perfectly natural.

So when you got the Duke of Edinburgh Award scheme gold award, what did you feel like?

It was wonderful cos my father was still alive and he was able to go to Buckingham Palace and he was actually asked to push me so he so he met the Duke of Edinburgh as well, and the Duke of Edinburgh remarked on the fact that he was in the RAF like the Duke of Edinburgh had been. My father had been in the RAF. And it was a super day. Again it was a November and a cold time of the year to go, but it was a lovely day and mum and dad both enjoyed it. I was so glad that they were still both alive because dad died 22 years ago really and it's a long time ago. So he missed most of the things that I've actually done since, if you see what I mean, which mum was able to see some of but not all of.

And so going to the palace to receive the award, and indeed from the Duke of Edinburgh, that was fairly unusual I think, was it?

Well it wasn't so unusual in those days because they held them at the palace in those days, then they transferred them to St James's Palace. But it was still fairly in its infancy even then; it's far less in its infancy now and, you know, I think they're much more security conscious and everything else. I mean I had a wonderful time. We went up in a lift and the equerry told us and he took us round the back ways and we could ask him questions about, you know, he took us all past all the offices and everything, and he even pointed out where... when she was in Buckingham Palace. Which all added to the day. And, it was super day, it was really nice. I'm very lucky because when I go to anything like that I manage to keep very calm, which is quite a help cos it means that I can take everything in, whereas if I've got me knickers in a twist, or less calm, I wouldn't be able to enjoy it as much. And I do, I literally store it as a very happy memory.

So what year would this be Dorcas?

Well it would be early seventies. You didn't get the Duke of Edinburgh's Award... you got it locally and then you went to the palace, or you had to wait so long to go to

the palace. So I got it and then went to the palace, and I think there was quite a gap between the two; I don't recollect how long though.

And so this set you with the idea, did it, of pursuing further involvement in the community?

Yeah. I mean, I don't think my involvement with the community has always been about disabled people, it's been about people, which is perhaps more important because I don't distinguish the difference really between disabled and people. We're all people. What makes it so different is people's attitude towards disability. That is where you get the differences and that is what you're trying to do all the time; make people aware. And I used to do, I used to give talks at school which were very involving. Any school that wanted me. And I loved doing that. And that is something that is very much missing now and I think it's a pity because I think when I did to the schools they remembered it because I always try to associate with people what they do to what I do. Like, I tell them that I eat baked beans, I tell them that I go to the cinema, I tell them what films I've enjoyed, I tell them that I can compute, I tell them that I used a typewriter, I told them that I went swimming, I told them that I go camping. And I can generally strike something that somebody had done, or more than somebody, that practically all of them had done. Then I would tell them about some of the problems of being disabled, like knowing somebody that hadn't gone out of the house for 15 years, and most of them were under 15 and couldn't possibly... I mean they go out every day and how easy it is for them to go out and how much harder it is for anybody with a disability to go out. So, because I could strike the right sort of balance and make them feel comfortable, because it is about making people feel right, I think they accepted it far better and would often say hello to me in the street. And I meet people now that I knew years ago that say they haven't seen me for years and they say, 'Oh, how good to see you. Do you remember such and such?' you know. And it's a very sort of rewarding thing. It's hard work because you have to keep updating yourself and updating the ideas and updating the language and trying to get it across to people, but there's less involvement with young people which I think is a bad thing. I don't think that's a good thing, I wish there was more involvement because I think we need that involvement because I think that involvement is very important. I know there are more opportunities for people with disabilities these days

but it doesn't make up for the fact that young able-bodied people seem less informed than they were.

And so your involvement with schools, talking to schools; did that then arise through contact with what was then CSV?

Yeah. It arose through doing Duke of Edinburgh, it arose through somebody hearing me and passing the word on that I could talk about disability, it arose where teachers were particularly with it, whereas sometimes it would be as simple as they were talking about the wheels and they knew I had wheels on my wheelchair and, all sorts of things connect to disability and I think that's good because it's a different way of looking at things but it still is effective, it still means something to the people and it certainly meant a great deal to me to go around and do it. And I was very glad that the schools involved me in this way.

And you were involved as well then with local youth groups?

Yes. I mean I also give talks to youth groups. I give a lot of talks to older people's groups because they need cheering up. I mean, I think a lot of people when they're older do not have life as easy as people think they do, and they need to be suitably encouraged and given a cheery afternoon, you know, saying what you've done, making them laugh about things that have happened. And all the things that have happened have happened to me.

So, when you -

So...

Sorry. So when you were involved particularly in youth work locally, you were still then a young person yourself. What was your aim in being involved in youth work, in particular youth groups?

The need to encourage people to mix, to integrate. Because I don't think people do integrate far enough, and I don't think people see the problem until the problem is put

under their nose. And I wanted to make sure that people who were my age had all the opportunities without the hassle, if you like, and I think it gave me a good deal of satisfaction because I felt that I was doing what somebody would do if they were paid to do it. It didn't worry me that I wasn't paid because I was recompensed in a way by meeting people and by being accepted. I think it was trying to get people to be accepted that was important. I still think it's as important because there's still people out there today that are floundering about that have low quality of life, and we want people to have a good quality of life. But there's no purpose in being disabled if you don't get a decent quality... I mean there's no purpose that you've got to achieve to get a good quality of life because that is the... There's a reason why we're disabled. And I reckon that one of the biggest reasons that people are disabled is so that they can improve other people's thinking on the world.

And, as well, you were continuing your involvement with Phab. Just describe to us then at this sort of time (besides aspects we've already covered about the courses) again what was your involvement with Phab?

Well I was secretary for the very first Phab that we had that was on at Northampton. Unfortunately it wasn't as easy as it could have been. Partly because I'd done things and other people wanted to do things and didn't. In the end I decided that probably the best way round it was to sort of set my own Phab up at Kettering and I did, and I was involved with that for 19 years. I gave up in the end because I really think I'd run out of ideas. And you do eventually, you do run out of ideas, you do get tired and I think when you start to get tired it's the best time to say I'm going to do something else and I'm going to change directions and I'm going to get involved with something else. I think you've got to make those sort of decisions, you know, you start making decisions about getting involved. You've got to know, you've got to realise that there's a cut-off point somewhere.

And so when did you set up the Phab group?

After the other one had been going – some time in the seventies. I can't remember exactly when. And it went like... I never had the same problem. I never had the problem that I did more than anybody else. I think it was because people were

beginning to do more things anyway, and in the process of doing more things they realised that they could do the things whereas I don't think that was obvious to Northampton; I think they just got jealous because they couldn't do the things or they didn't connect that they could. They could have done but when a person had no sort of feelings about you, you can't make them see what they can and cannot do.

And so Phab, of course, Physically Handicapped and Able-Bodied as it was originally described, and mid-seventies; were you finding then that more disabled people were more able and more willing to join groups like Phab?

Yes, but I also think there was more opportunities for other people to do other things. There's even more now but it's still Phab, because some people just can't do that manoeuvre. They can't see how they can move on. Or they're not in a position to go and discover how they can move on. And lots of people are still very isolated units of people. You know if they haven't had anybody give them any encouragement – possibly even their parents haven't been able to give them the encouragement they need, or even the school people or anybody, then they don't get encouraged. Because it's having encouragement that helps you to make the first step. Once you've made the first step then other people come along and it gets a bit easier, but the first step is always the most difficult in any decision.

And, of course, crucial to the facility to get out and about, apart from anything else, is the degree to which the built environment is easy to access or not, and you worked then on an access guide as well.

Yeah. Access guides are very important because I think access is the thing that stops people going out and about. If people can't get anywhere they get frustrated, which is why so much of my Phab time was spent raising money for ambulances that could take us out and about – or vehicles or minibuses or whatever you care to call them, just to take people out. Because there was just no provision at all. I actually have taken lots of people who've never been in a train on a train, because it was never thought possible that they could get on a train. And anybody can get on a train if they're willing to do the planning properly. You still have to do the planning properly, you still have to ring up British Rail and book a [seat?] or whatever you, you know,

and it doesn't always work as easy as I'm saying it to you now, and for lots of people that is unknown quantity.

So with Phab then, locally, what where some of the things that you used to do?

Have people talk to us about various hobbies, cooking, go to the theatre, have films, go out to other youth clubs, go out and have a party, go out on as many occasions as [possible?] – bonfire night, Christmas parties, birthday parties – any excuse to get people, other than Phab involved really. And just chat, do quizzes, do all the things that everybody else does, you know. Go to a pub even. I know we had one or two people get drunk but it was never a big problem because most people who were on tablets knew they were on tablets and were sensible about it. And I always used to say, 'If you don't want anything else have a soft drink,' cos they'd do soft drinks. And, you know, we never had a great problem.

And in terms of, you know, how you raised money; what were some of the ways you used to raise money?

All sorts of things. We did a walk to Oxford; we did a walk to Norwich, being pushed...

[End of Track 13]

Tape 8 Side B [Track 14]

We slept in various places. We slept in somebody's house, slept in an old youth club place and thoroughly enjoyed it. I mean it was a real challenge and it was... I think after I've done a challenge I still do... challenge. But I'm much more aware now that there is even more need for outsiders to understand, you know, because there's less things offered to you on a plate, as you might say. You know, you need to have to be aware of where people can get help, where people can get wheelchairs, where people can get doctor's appointments. You have to be prepared for almost anything. And even if you don't know the answer, you have to know somewhere where you can point a person to so that they will get the right answer.

So starting out from Wellingborough then, to places like Norwich and Oxford, you're talking quite a distance in both cases.

Yeah. I mean, one took five days, the other took three. Cos we paced it and, you know, we had frequent stops. We stopped one night and I slept under the awning of a caravan while the others were in the caravan, cos I couldn't get in the caravan, and the television aerial fell off the caravan, frightened me to death cos I was under the awning, I thought somebody was trying to get in. [Laughs.] I said, 'Help!' and they all flew out of the caravan. [Laughs.] And luckily it was the television aerial fell down, you know, all sorts of things like that. I mean, the number of funny things that have happened to me are incredible.

And so in terms then of your, as I say, other involvements, particularly then work on this access guide; when did that come about?

Because I realised that without good access to places people aren't going to go out anyway. Access is not just about disabled, access is about everybody. Mothers with double buggies, mothers with prams, people that find difficulty in walking so hold hands, people with learning difficulties, people that access a doctor's, you know, they want to know which room to go to. Access plays a very big important part in everybody's life. They don't realise it, they think it's just about external things, but it's about internal things and it's about freedom to get about. And if you haven't got

good access you can't get about. I mean you can't get up kerbs if they haven't got enough dips in them. And, you know, I've watched people over the years, I've watched lots of people struggle to cross roads, to get up kerbs, pushing wheelchairs when they shouldn't really be pushing wheelchairs because the person they're pushing is heavier than they are, or they're perhaps infirm and the person they're pushing is equally more infirm, and, you know, it's very difficult... it encompasses so much. Which, if a place is more accessible it helps the trade of the place, it helps people see it, people are much more likely to go in and buy something, people are much more likely to go back there rather than struggle up steps or struggle down steps or be served when they're outside, you know, when they could be inside, and it's a whole lot of issues, it's not just about getting out and about, it's about what you do when you get out and about, where you go when you get out and about.

So you work on this access guide then. When did that start?

Well I did the first one when I did my actual CSV, for CSV. I was a volunteer, and they were willing to pay me a wage and I said, 'No, put it towards publishing the guide,' cos I knew my publisher could. I'd already had my book published so I was already involved with knowing a little bit about access and I was asked to do it by Northampton Youth Council for the Disabled. The first day I went into the Social Services department, told the lady that had got... if I could do something about access, told the lady that I was starting to do it, and she immediately said, 'Oh don't just do shops, do as many roads in Wellingborough as you can.' So I ended up doing a lot more than just the shops. I ended up doing virtually all the residential streets in Wellingborough as well. Which doubled the size of the job immediately.

So just to recap; it was an access guide then for Wellingborough, and the funding was coming from Community Service Volunteers?

Yeah. It was coming from there in lieu of my wages because I didn't take the wages. And my friend published it. It took an awful long time to type up, because I did all the typing and it was a wonderful year. I mean, towards the end I had a young lad push me for work experience and we got on like a house on fire. And he said it was one of the best work experiences he'd ever had because we got on so well. And yet he

wasn't particularly good at school so I had to remember quite an awful lot because he couldn't put it down so easily as some of my other people that had helped me. But we got it and I can show you a copy of it.

So what year was this, Dorcas?

'88 [1988].

And so you'd go round different venues, different streets and you'd...

You look at the pavement, how many dropped kerbs there were, how easy it was to cross, how hard it was to cross, went into buildings like churches, went into shops, did what I could. The trouble is anything like that is out of date before you even print it, so I mean, it didn't have a very long shelf life, but it did generate some interest. I was quite glad about, and I'm still glad. I'm very glad that I did it because I think it needed doing.

And at that time then – late eighties – there was just the beginnings of an awareness that things should be easy to access. Were you aware of this developing trend at the time?

Yes, I think I was aware because I'd already been involved with Northamptonshire Council for Disabled People and I think that made me aware. I mean, that's another committee that I've been on for a heck of a long while, and I think they were getting more aware, and I think they wanted me as chair to do something about it. And I thought well I want to do something about it as well because I didn't know quite what I was going to do. I mean half of it was – when I got started – formulating what I was going to do. I'd go out one day, perhaps one or two days, and type up the rest on the other days. And, you know, it wasn't easy, it certainly wasn't, it was a challenge and it was enormous fun. I think I got through more pot noodles in that time of my life – I don't eat pot noodles now but I had to have something during the day – and sometimes I'd end up eating, just having a drink and something with it.

And so your involvement then in the Northamptonshire Council for Disabled People; when did that come about?

That came about through Social Services. They were looking for somebody to start one up because they were... The county was having branches and the branches were attached to the county, and it was organised by a person called Cecil [?], who was disabled himself, who was retired. And I saw the need for employment opportunities as well as other opportunities. And it grew from there because the social worker I had at the time was brilliant, was one of the best social workers I have ever had. She was brilliant. She's moved now, she's no longer... And she encouraged me to get involved, and it was obvious that I think they were gunning for me, [laughs] if you see what I mean. I got to be chair and...

Of -

... of the Wellingborough branch, and stayed like that for quite a while. In fact 15 odd years. Then I was vice-chair, then I went off, now I'm the [?] person. But branches need re-shaping anyway because now we do things at a much more county-wide level, the branches are still around but not as many branches and we tend to do things more at a county-wide sort of basis, with the local input from Wellingborough.

So how did this structure work, then? You were set up by, or with the encouragement of social services, were you? The council?

Yeah. The idea was that so many people with disabilities were involved and so many organisations for the disabled were involved. And that could be anybody. That could be the police, that could be the fire people, that could be people in social services, people in health, the library, anybody that really wanted to know more about disability joined the group, with some willing people to be treasurer and secretary. And we met in a variety of places with a variety of people – came and went, like ebb and flow, like you do in all organisations. We tackled the local problems and anything that was bigger we took to Northampton and told them, told the county [branch?] about what was going on. And they in turn fed us information back. And it's amazing really, I mean, it got to be a regular hotline between organisations. And that was really

why we did it. We wanted to, erm, Northamptonshire wanted to have this in-borough organisation, so that people could contact people easier, so that you knew where to go for so and so, or you knew where somebody knew that there was a possibility of going to some. And you had people to contact if there were problems and it made life a lot easier in some ways when you were fighting to get things done.

And this was of course before any legislation was on the statute book; disability discrimination legislation. And was it at a time when there was just then the first coming together of groups to look at issues like access; individuals as well. How did you feel about then being involved in the Council for Disabled People in Northamptonshire, and rising as you did to be the chair of the Wellingborough group?

I thought it was a wonderful idea, a really good idea. Because I had done a little bit of research into this organisation for disabled people, and I had found that a lot of people were duplicating the same work. So a lot of money was being spent on duplicating the same sort of problems, which is a waste of money. If we can work with each other we save money and you give a better service because more people know about you. I mean, this is where the blind organisations scored so high because after the war they got together and they got their act right. Whereas there are so many fragmented organisations for specific different medical disabilities, who won't think about going together, and to me that is hard work because you're having to deal with each one organisation whereas if people shared the information – I always share my information – [it] makes it a lot simpler because then you know what people are doing and you don't do the repeat thing. You leave them to do what they're doing and do it to the best of their ability, and perhaps give them a bit of encouragement and tell them, possibly guide them into the right channels and that sort of thing, but that leaves you free to do something else that equally, definitely needs doing, that nobody else is doing. And I think organisations have got – of course they've a right to be individuals – but they've a right to share information as well. Because I think that is really, really important.

And in terms of their reaction to your work with the Northamptonshire Council for Disabled People, and indeed the access guide as well; what kind of reaction did you get from that work?

Well I got positive reaction from Northamptonshire Council for the Disabled because they were the ones that were the thinking behind it. I mean, not necessarily the total thinking behind it but they were the ones that started the ball rolling as you might say. The reaction I got from other people was very, very... the council were surprisingly supportive, I think because I was an individual. I think sometimes the county council were quite supportive, I think that helps. Not the county council, the borough council. That helps. If you get support from there at least you get positive reactions from councillors and people like that, which you need on their side. I remember the very first time I went (after I'd done the report) to tell them that it was done, and there were some major things in Wellingborough that needed doing – major road, big dropped kerbs and things like that – and I went to see them and we had to have our meeting in the park as the building where they did their business wasn't accessible – it's still not accessible but now I wouldn't have to have the meeting in the park, I'd have it in one of the rooms that is accessible – they hadn't got their [act?] together enough at that time. And he met me in the park and he said, 'I guess you've come to troubleshoot.' And I turned round to him and said, 'No I'm not trouble shooting anybody; I've just come here to tell you a few things that need doing.' And because I was quite calm about it – I didn't say yes I have come to troubleshoot and I'm going to cause you you know what, which has never been my way anyway, I don't believe in doing things that way – because I went at it saying no I'm not here to troubleshoot, I'm just here to point out a few things, it got done. And, I mean, OK I was made aware of one or two things that I hadn't been made aware of before, like they're more likely to do things in the town centre than they are outside of the town centre. They work from town centre outwards, so if you want anything done in the town centre it generally gets done first and generally gets priority cos more people are going to use it. But once I told them what the problems were – I mean, there's still one problem they still haven't solved and that's a 23 year old problem.

So in terms of, you know, awareness amongst planners and engineers and builders and so on, this was in the very early days when that kind of awareness was just

becoming established I suppose. So were you called upon then to be, if you like, the expert, the person that people approached?

Yes, sort of. I think a lot depends how long the people stay in the post that you've approached. I mean quite often there's changes and with changes they don't necessarily connect you. So, yes, to a certain degree, although it's changed again since then because now everything has to go to county council, so it's a lot harder to get things done because it's not a local person you're talking to, and they can't see the importance of it. And really it's not as easy now at county council as to when it was local borough council, because you can get one of their building regulation people out... whether it could be done, not when it could be done because that depends on the pot of money. But, you know, at least then you could get them out whereas now the people are changing continually and it's much harder to get them out from the county council than it is from local.

So...

You know...

So...

... it's just one of those things. It's all to do with progress and sometimes things aren't very progressive.

So in terms of, you know, being called upon to offer advice about things to do with access and working on the access guide, being involved with other disabled people in urging that things should be more easy to access, how did that contribute to your own sense of self?

I think it made me feel useful. And I think I needed to feel useful. I think when you don't have a job it's so easy, in a pressurised world where work and being married seem to be the top priority, when you don't do either you've got to have some sort of fulfilment otherwise you tend to over-dwell on these things and then they become a psychological thing. It has never become a psychological thing with me, which is why

I've got the friends that I've got because I think about other things the majority of the time, you know. [Laughs.] I've got friends, I've got men friends, I'm quite happy, if a men friend don't want to get involved, or on whatever level they want to get involved, they get involved. And that is it. You know, I mean, it doesn't stop me wishing sometimes that things were different, you know, that things were a bit more... that I had perhaps a special man friend. I've got two special men friends but they don't want to get married or anything like that, they want to still continue with where they are, and so be it. I had it drummed into me when I was school so much that it would not be possible that that coloured my life for so long about what was possible and what wasn't possible. And, until I got my two special men friends, it took a lot of getting rid of. I think I was carrying that round as a bit of excess baggage for quite a while and now I've got rid of it I'm completely calm about things. What will happen will happen. What doesn't happen doesn't happen. It's no use getting in a state about it cos you can't change it, you can't make people do anything. I've come to the conclusion, you can't make people do anything that they desperately don't want to but you can have an understanding with them so that they know where they are and you know where you are, so that it's possible to have a perfectly good understanding without getting a state about it. And I think that is the most important lesson that anybody could ever learn. It saves a lot of grief and a lot of unnecessary wishing about something that you can't change.

And when you were doing your talks to school students – secondary school students I guess in the most – what were some of the sorts of questions that they were asking you?

Well, they ask me have I had a boyfriend, did I have sex, what sort of sex did I have, did I regret being disabled, what was the worst thing that they could do to me – pat me on the head. [Laughs.] I've got friends who do it but I mean at least I know they're friends [laughs] and I know where it's coming from. They do it just to see my [reaction?] But I think every person with a disability needs to know a few people who they can communicate with when things get rough because things do get rough. I mean, occasionally when things have gone badly wrong I've sat and wondered what on earth I do it for, but then I'll go to bed and get up the next morning and I've got myself together again. And I think that's what you've got to do because it is so

important. I mean I don't underestimate what I do. I don't do it for the glory of doing it; I do it because I see the need. You know, and I don't want to be one of these glory people who do it for the wrong reasons, and I don't do it for power either cos I've got no inclination for power at all. I just do it because I know it needs doing. And because I know what some of my friends have been through – the hassles that they've had. And I don't wish anybody that kind of hassle because that is not what disability is about. You're not here to be in a sense systematically destroyed. You're here to build.

And as we've seen over recent years again the growth of a feeling amongst some people with disabilities that having a disability is something that people want to proclaim to others. What is your feeling about that development?

Each and everybody to their own. I don't think I want to proclaim my disability so much as I want to make people aware. Cos people still go round patting me on the head, the still think that I'm not quite 100 percent with it some of the time. I mean, OK I'm getting older now, [laughs] but, you know, I can only work with the people that I am given help to work with. And possibly with using the computer it's more written now that it ever was before. And I don't just mean by books but I mean by emails and that sort of communication. I've got a steady little pile of both able-bodied and people with disabilities who I email every day, if I can, even if it's only an e-card to say I'm thinking of them. Because I don't think disabilities... I think able-bodied people have just as many difficulties. I come to that conclusion a long time ago. So my answer would be my help is not specifically for disabled people, it's for anybody. And I think that's something that I've become much more apparent in the last 15, 20 years than it did when I first left school, because of the way things are. I think disabled people do have problems – of course they do – but I think able-bodied people also have problems and less avenues to go down to solve their problems. Hello, is this somebody coming here on a...?

And before you had computers – which we'll perhaps come on to shortly, Dorcas – you used, did you, mainly a typewriter?

Yeah. An electric one. Yeah, hard work. Hard work because they're not as adaptable as computers, you either have to push the carriage across or press a button and it used

to go across. Hard work because of correcting things because I can correct as I go along, I very often do that because it saves you from correcting a whole manuscript. I don't always spell-check. I've done the thing, but I always correct as I go along cos I find that easier. Yeah, very much hard work. I suppose in the days I had a typewriter I had more time. Now I've got so I sit [on] so many committees, I mean I'm on 10 because I help with the local Saste, Local Strategic [?], which involved Wellingborough, which is the modern way of input into what goes on in the town. I'm on the health and well-being one, I'm on the equality one, and I'm on the... erm... sustainability one.

This is the borough council one is it?

Yeah. It's borough council. And I see all the same people at most of [the meetings?] because that's the way things go. But I like being involved a bit in my town; I don't get any funding from those at all. I mean, if I'm taken I'm taken. It has to come out of my pocket. But at least it's Wellingborough whereas the other organisations; Sequal pays me to go to their meetings, Ability Northampton pay me for any meetings I go to for them, The Independent Police Authority Group that I've just recently joined the most recently, they pay me, I'm on that.

[End of Track 14]

Tape 9 Side A [Track 15]

So in terms of, you know, being able to gather information and receive information for the various work that you do, now you find, do you, that with a computer that's made that much easier?

A lot easier. A lot easier to communicate to people, a lot easier for people to communicate with me and me to give them the idea, rather than to dictate it to somebody. A lot easier to look for things; information that I want. Shopping. I find I can generally find something on the net. I've had one or two bad experiences but I can't think of anybody that hasn't. You know, and when I say bad experiences I mean I haven't lost a lot. I'm careful what I do and who I do it to and, you know, I think mostly it's the post that fails to deliver things so I have to go chasing after them. So nine times out of 10 I get the things replaced anyway.

And on a typewriter or indeed on a computer keyboard, how do you type?

I type with a stick in my mouth. Plastic knitting needle. Metal knitting needles would wear my teeth out so I tried plastic and they are the best needles because I can bite through them and they don't damage my teeth particularly. And I'm like Woody Woodpecker: I tap the keys. You know, bobbing about. [Laughs.] I do get tired, I find that it tires my back more than it did, but then I've had one hip removed and that means that I sit awkward anyway, which does not help the other hip, which does not help the pelvic bone and it's the pelvic bone that's giving me the pain at the moment and I'm on pain killers for that. And if I do too much computing it hurts more. You know, but, you have to. I can't not use the computer; I have to use it, because it's so important. You know, if I was [inaud] on a dessert island, as my friend says, he would let me take my computer.

And in terms of, you know, communicating with others and telling them of your life story, you published then a number of booklets. What's been the story of those?

Very early on I was told that if I could write a book it would help the community because I knew so much that people didn't know. And I thought about it and I thought

no I don't really want to do this. But I was encouraged to do it. And also I thought I hadn't got a clue how to begin. And I got there. The first one took seven years to do, they're now much easier with the computer, but I still have to be in the right kind of mood to do it. I tend to do a block and then put it away and forget it for six months and then go back to it and see where the faults are, because I find that a lot easier to cope with. I think when I first started writing, people wanted a 'sob story' and I wasn't prepared to give them a sob story because I think that's a downward thing to give. I think a much more positive thing to give is to say, 'Look I'm here. I'm coping. I can do it. I may be disabled but I still have my worth. I still have my values. I still have my rights. I still have everything you have.' Because there's lots of things that happen to able-bodied people that happen to people with disabilities as well. And the people with disabilities don't have the same kind of backing, so that when these things happen nobody gets up in arms about them, but if they happen to a person who is able-bodied, everybody goes up in arms. And it's a different story altogether. I mean a few years ago when I bought this flat, I've only been here just a little over four years, four and a bit years, I went and got the flat, I went to the estate agents, and half of the estate agents I went to in Wellingborough had never see a disabled person. I mean some of them had, because some of them knew me anyway. Some of them just hadn't got a clue. I went into one of the estate agents in Wellingborough and they did all the talking to my carer! And I just got out of there and we both burst out laughing cos he was a riot, and I said, 'I don't think we'll be going in there again.' And he said, 'No I don't think we will and I don't think we'll bother to look at houses in there either.' And we didn't. We simply gave it a miss. One of the estate agents I couldn't get into anyway and I gave them a miss, and I found one through my old friend, who I'd dealt with before when mum and I had moved. But I mean some people thought I couldn't possible know what I was doing to buy a flat, but I knew exactly what I was doing and I knew exactly what I wanted. I wasn't going to be fobbed off by somebody saying I was stupid, because I knew darn well I wasn't! You know, and it's those sort of things where you've got to be a bit tough. You can't let people ride rough shod over you like that. If you did it to them they'd be up in fury. You know, they'd really go up the wall; they'd do all sorts of things. But they don't think about it when they do it to you, and that is what I mean about people not understanding about what disability's about. I mean, OK we know there are some people who are disabled who probably wouldn't want to buy a flat because they wouldn't want to go into that

responsibility or they wouldn't want to do it without help or they wouldn't want to do it at all. But I mean that is up to the individual person. I am no less than anybody else. I am no more than anybody else. I am just real, you know, and that is what it's all about.

And so in [coughs] publishing the booklets that you have, telling different aspects of your life story, what has been your motivation to publish those?

Still people not understanding, needing to know, and needing to know the positive, not negative. Cos so many people need negativeness. So many people think that because we're disabled it must be a sad thing or they must offer you pity. Well I don't want anybody's pity; all I just want is a bit of common understanding.

And what kind of reaction have you had to their publication?

On the whole good because people can read them. And they're not masterpieces, they were never meant to be masterpieces, they were just meant to show people that there is hope even when you're disabled. I think that's the main thing because I think it has made a large... I remember hearing from a particular friend of mine who I don't see but who I hear from, who said that when her son was born disabled she knew that she could cope with it because she'd met me and read my book. And that's what it's all about. That is the positiveness of it, that you help somebody go through something – my parents never had that chance. I mean my parents never had anybody; they just had their own wits. And I owe it to my parents, a tremendous amount to do what I do, which is another reason why I do it. Because I owe it to them to prove that them keeping me when they were told to forget me, it's immeasurably important to me, it's what keeps me going.

And each page, as well, we should remember of the manuscript, or the various manuscripts typed by you.

Yes. Yeah. The first one was ghosted, but it was by me in the main. I realised that he had style that [I] never had, but then people who know me say the book's me. And that is what I wanted them to be. I don't claim to have any literary deed. All I want to

do is to make it possible for people to have an insight into something that's not negative. I could write about negative things, I could write about some of the terrific problems I've had. And I have had them, but I don't find it encouraging. I don't think that the type of people that read my books would get encouragement from the negative things; they get encouragement from the positive things.

And in terms of your reaction to the medical advice that your parents were given – forget her – what are your thoughts about that now?

I wish they could see me. In some ways I [wish] that I could have done more. Not more in terms of... I wish I could have done some paid work giving people help. You know, advising people, getting people into society, because I think people do need help getting into society, particularly when their quality of life is less than what it should be.

Yeah. And if again we take the situation for people now – obviously individual circumstances are just that, individual – but generally how do you feel that the circumstances may have changed for somebody with a disability now, as against somebody with a disability born when you were born?

Oh I think there's much more opportunity now than there was then. But as I said to you before, I think I was born 20 years too soon, therefore I've got to... I mean I would have loved to have studied to become a minister or a vicar, because my faith is such a... I think I could have done a good job. But I'm too old. I mean, I know it's not fair to train somebody and then be at retiring age. So, you know, that I've talked over with people and it's just a bit silly really, it's just something that came too late, you know. Like lots of things come too late but you don't dwell on them, you just keep going and you just do what you know you can do, and what you can't do you can't do much about.

And in terms of your faith, how important is that to you?

Everything, I think. It's undergone some major changes since my time [laughs] when I was at school. I'm comfortable with a lot of different religions, I can go into any

church in Wellingborough and feel comfortable and I very seldom get put out. I'm a bit of a spiritual tramp in that way; I see other people's points of view as well as having my own. But for me it's everything because it keeps me going. Not just for myself but I can pray about other people as well and I find that that's good to do. Because when people are having turmoil they don't always want to pray or know how to pray or even think about it. And so many people are not religious these days, or say they're not religious whether they're... I mean I think everybody turns to God in desperate circumstances. But I still think religion is important.

And, in terms of, you know, your awareness of you and, if you like, of those around you; what kind of strength do you draw from faith, then?

Because I always find that there is always one door opening after another one's closed. It might not happen immediately but it does happen and when you've had a particularly bad day it can only be as small as somebody coming up to you and saying something right that puts you back on line again. And I find that happens time and time again. And it gives me a tremendous amount of strength because I know people care. And people care because I care. It's funny, caring is having, giving care you get the care given back. And so it multiplies and so it's a wonderful thing.

And in terms of your own situation now in Wellingborough; you started off living back with your parents and then your father died so this left then you and your mother living together. So that the years came, the years went and that then proceeded and you've told before about the aspect that you then felt that you became (in part at least) the carer of your mother.

Yeah.

What then was the next stage in moving towards schemes of what are now called independent living?

First of all living without mother, and I can't tell you really a lot about that because I coped with it just as I coped when dad died, because I knew that I had to. And if you know you have to you do. The second thing was a very pointed remark made by a

friend, 'Why don't you move somewhere smaller? Because you'll have finance as long as you are paying for your own care.' Because I just wanted that freedom so I did it. And I was glad I did it. I didn't need the money, in a sense I did need the money because I'd spent mum's money, and mum and dad saved hard for that money and it didn't last them anywhere near the length of time that they thought it would. And my money from the bungalow, having bought this which was much smaller than the bungalow that I lived in, and much more economical, having bought this place I'd got 50 thousand [pounds] which enabled me to sort the bathroom out in the flat, and one or two, and get new windows and doors in, and also enabled me to live another year without having to be means tested and all that business what you have when you haven't got anything. When mum died I got my own transport, which was an absolute Godsend cos I was paying a fortune like taxes and things like that, and it really opened the doors. The doors have closed slightly I think lately because of the lack of money, but we still keep going. I may have overdrawn on the odd occasion but I've paid it back, and that's how I go on. I do sometimes wish that I'd got a bit more money but then I know there's far more people worse off than I am, so why worry?

So in terms of personal care, you know, once your mother had died, how did you go about putting that in place?

Well I'd already had care cos mum was getting to the point where she couldn't manage me. I'd had young females. When I decided that males were better because I was having trouble with females, I've had a succession of male carers, which are much better in terms of how they cope with me, and they're less 'dramatic', in a sense, and it's not like having two women in charge. I mean, I sometimes think two women in the house – even if it's a carer – can sometimes want to be boss when they're not boss. When you're paying people you're the boss. And I don't mean that nastily, cos I'm not nasty in that sort of way, I just mean that I am responsible, I am an employer of people, you know. And I've had so many ups and downs with all that; that would fill another book. But that would be all problems and that whole... I don't really consign to put in books, if you see what I mean. I know it would probably help other people but I don't think problems do because I think everybody has different problems, you know, and unless they ask you specifically, 'Have you had that problem? How did you tackle it?' you don't mention it.

And so, you know, you were determined were you, to remain living independently with care provision and you were in the circumstance were you, initially, as well of then paying entirely for your own care?

I paid entirely for my own care until three years ago, then the money had gone. And it, no, possibly four years ago, then the money had gone. And I had to go through all the system again which nearly drove me mad because they refused to see that I'd been on the system before so it wasn't easy and I couldn't get back on the same... oh, it was a nightmare, absolute nightmare, and still is because still when things go wrong like pension don't get paid in when they should and things like that, it's still a nightmare. They still think you're trying to defraud them of something. I'm not out to defraud anybody. I like to make them aware that they have made these mistakes because I know how much dismay it causes other people that can't stick up for themselves. And that's why I'll always do something when it happens to me because you need to make them aware that their foolproof system is not foolproof!

And so how did you set about then, you know, constructing a pattern of care in the first place?

Well, I'd had care at Osborn Close [Wellingborough] so it just changed when I moved here. I've had care for the past nine years like, you know, so I've coped with it. I mean it wasn't that dramatic. I think things have been more dramatic lately, this last year, but I mean it wasn't that dramatic and I just was determined to do it because I knew that's what I had to do. I didn't want to go into a home, I still don't want to go into a home, I've got far too much to give and to do before I go into a home. I mean one of the greatest pleasures of life now is my committee work gives me pleasure, and so does my involvement with the local theatre, because they accept me on the board as a person. I might be disabled but I'm still a person on that board and I'm not specifically there because I'm disabled; I'm there as a board member. Which is great because it means that I've achieved what I originally set out to do which was to prove to people that disability need not be disabling, in a sense. You know, you can't win all the battles cos all the battles aren't winnable, you know, in terms of what you can and cannot do. But you can win a vast majority of them, which gives me great satisfaction.

And in terms of, you know, to return to the care scenario; how did you go about finding carers and setting up a system of payment?

That was very difficult. It's getting increasingly difficult. I'm going to have to do this when I get back from my holidays cos I'm one carer down and I have been for a year now. But that thereby hangs a tale which is too complicated to go into at the moment. You know, it is difficult to get care, particularly when you want it for just more than getting you up and putting you on the toilet, when you want it for going out and feeding you. But I've been very lucky in that respect I suppose, I don't know whether it's luck, I don't know whether it's judgement. I've had my rocky moments, I really have had some; I've had two people walk out on me, which weren't because we had a violent row or anything like that, they just decided they'd had enough. Weren't man enough to say, 'Can we go?' they just walked out. That was nothing to do with me. You know, I mean, honestly I can say that and I say that and know that I was right in saying it, d'you know what I mean? I don't feel guilty about saying it, it was just that things happened and that was it. I do sometimes think people lack guts, they can't tell you things straight, they have to go round corners to tell you things or do things drastically. You know, they can't be honest and say, 'Look we've had enough. Can we leave?' they've got to do all of full 'dramatics'.

Can we cover the award to you, the honour of receiving an MBE? How did that come about?

It was all done and I knew nothing about it. [Laughs]. And I can honestly say that until I got the letter through the post in June for the queen's birthday honours in 1999, and I nearly fell out of the chair, I went a whiter shade of pale and my carer said, 'What on earth are you hearing from the Prime Minister's office for? What have you been asking him?' Cos I had written to the Prime Minister on one occasion and he thought I'd done that, and of course when we opened it, I read it, I just went pale, and we had to hide the letter because they tell you not to tell anybody, you see. And that's awful when you're disabled because the person that shows you the letter is going to see it anyway. I had to swear him to secrecy. I was in Canada on holiday when it was announced, I told my other carer a few days before I went, so that he was aware, I told

my other carer a few days before I went, so that he was aware, so that I could get the newspaper cuttings, I told one of my best friends and he twigged what was going on cos I said keep the cuttings around I said a certain date. He still put two and two together. I don't know how because I didn't say anything about the Queen, Buckingham Palace or anything like that (I didn't meet the queen actually, I met Prince Charles but), I didn't say anything, all I said quite innocently, 'Will you keep,' I said, 'the papers around so and so', and he's just twigged it so whether he'd got an inkling beforehand I don't know but I certainly didn't have an inkling before. And it was absolutely terrific. It was terrific because A: it was at Buckingham Palace, B: I saw one or two famous people, I enjoyed it immensely, it was absolutely wonderful. I took three friends with me including the friend that organised that I should get the MBE, who's a good friend of mine anyway, I took one of my carers with me, I took my friend who saved me the newspapers as a driver [laughs] and we had an absolutely marvellous time at the palace. We had an absolutely wonderful time over lunch cos we met Lady Jean Mackenzie, who I hadn't seen for a number of years, who invited us out for lunch afterwards. So we went scooting over to Westminster School cos they invited us for tea. And that was absolutely out of this world cos I met so many people involved with Westminster Phab [Physically Handicapped and Able-bodied; a charity encouraging integration within the wider community], it was really, really good. And the school means a terrific amount to me because of Phab and because I've made some wonderful friends there and I get on very well with the staff and everything, so I was really honoured. I was absolutely overwhelmed. And we had a party in Wellingborough as well, which was wonderful. It was absolutely great. My friend William Booth, who I showed you the picture of this afternoon, who was Chaplain at Westminster School, who was now Sub almoner to the Queen, he was on duty at St James's Palace, so he came across and said hello before the ceremony started, which was nice. He couldn't talk to me much because he had a very bad throat, so he had to write everything down. [Laughs.] But the meal with Lady Jean at the Overseas Club was great, even though I had to get carried up the stairs to the restaurant. Luckily I'd visualised some sort of problem like that so I'd got the two men with me who were able to lift the wheelchair up. The pictures in Buckingham Palace were super. I sat with a gentleman from Wales who got services for sports for the disabled, who was a rugby player, and he was nervous and I was a bit nervous but I was more nervous when it was my turn to go forward. I managed to keep reasonably calm until then and

take everything in, which I'm always glad about because it meant maximum enjoyment.

[End of Track 15]

Tape 9 Side B [Track 16]

And so what was the MBE awarded for, Dorcas?

‘Services for the disabled’. And Prince Charles asked me to give my regards to all the disabled people in Northamptonshire, which I thought was very nice. I was terribly nervous when I actually went to get the award, when he actually gave it to me, and my friends were all terrified that I was going to ‘biff’ him one [by accidental arm movement]. I didn’t, but yeah, everything else was beautifully calm and I remember everything. It was lovely, it was, I mean, you know, we had great deal of... What my guests or I didn’t see was one of the yeoman of the guards fainted, which all I heard was the clatter as he went down. When I got outside it was windy and quite cold and my skirt blew up and the person that saw my knobbly knees was a policeman because by the time we joined the queue for the photograph, we were right at the end of the queue so gradually people disappeared after they’d had their photos taken, and because we were at the end of the queue we were nearly the last people to sort of disappear, which meant that we had to rush to find Lady Jean, but we actually had longer to look round and to take stock, if you like. We were allowed to park in the Buckingham Palace Quadrangle, and mine was a little Renault white van I had at the time, and it was amongst all the Bentleys and the Daimlers and the Wolseys and the Rovers, you know, all the posh cars. There was my dear little Renault stuck right on the end. I felt quite affectionate towards it. [Laughs.]

And what did it feel like, you know, to receive the recognition that the MBE brought?

Amazing. Absolutely amazing. [Laughs.] And so unexpected cos until I got the letter I didn’t know anything. I mean it was the most closely guarded secret cos Pam, bless her heart, canvassed everybody. She went round the [Wellingborough] Borough Council and all their, you know, got them to say... I mean I don’t know where she didn’t go. I didn’t ask her, she just did it. I mean, I was absolutely amazed.

A friend of yours? Pam was a friend of yours?

Yeah, Pam's a friend of mine. She was my secretary when we had Council for the Disabled Wellingborough branch. So she had some idea of how hard I'd worked, you know, possibly more than anybody else. And I think she just felt that I deserved it. And I really don't know whether I deserved it or not but I was very grateful for it. I mean, I would never have said no, and my parents would have been so pleased. They would have enjoyed every moment I dare say, my dad would have said, 'Oh I told you so,' you know, 'I knew you'd succeed,' and my mum would have said, 'Oh dear, what am I going to wear?' You know, she'd have been far more worried about the actual day and my dad would have loved it. Mum would have enjoyed it but dad would have enjoyed it more. He would have. I mean he enjoyed going to Buckingham Palace when I got my [Duke of Edinburgh] Gold Award, rather more than my mum did. My mum was quite happy, my dad could meet anybody. My mum could meet anybody but the difference was dad was able to sort of take that sort of thing in his stride. But my mum was good to everybody. And I think I'm a bit of both really; I can take things in my stride mostly, and I can be the same to anybody.

*And, in doing the work that you do and have done, and in going to places, and having the leisure activities that you do, doing different things; what is your philosophy?
When you get up, when you greet a new day, what's your philosophy?*

Come on let's get to work, let's get it done, let's do what's do-able. I only occasionally chicken out of things. Sometimes if I'm not very good I chicken out of meetings because, you know, it's no good going if you're not going to give your best and if you wish yourself somewhere else. I don't chicken out of much. I mean, I went up to Yorkshire on Saturday and flew me kite with me friend and I didn't get to church on Sunday, but it wasn't because I didn't want to go to church it was just because I slept in later, and it would have been a rush to go, and I decided that I wasn't in the mood for rushing and sometimes I think you've got to make those decisions and I do. If I can't get to a meeting now because I can't find a driver, since I've only had one and a bit carers, if I can't find a driver I just don't go. I mean it's no good killing yourself trying to find people that just aren't there. You know, I mean you spend a fortune ringing people up. Well I have to get food in for me, when John's not here I have to get somebody to feed me and that sort of thing, and, you know, it is

[takes] quite a lot of organising that does. So, you know, I don't get so het up now if I don't make things and I certainly, if I really don't feel like it I don't do it.

And in your life so far, what have been some of the best moments, do you think?

Getting the MBE, travelling and having one or two friends that I've got, that are very special to me. I think they're the moments. But there's so many moments, you know. I mean travelling always brings its pleasures. Literally, little bits of things. Things when people say thank you very much or... you never know. I mean it differs from day to day, month to month, week to week, hour to hour even. I mean I can switch the computer on and get something a great kick out of [it?]. I went to Peterborough last Wednesday to the St Peter's Tide Service at the Cathedral and that was organised by a friend who was going; that was wonderful as well. You know, so different things do different... And it's very difficult to say what you think is best cos I think it depends on the mood at the time as well. I mean at the time you ask me, I mean I could think of hundreds of things. But I think it's a good thing that I can think of things because it means that I'm satisfied and I feel I've got to where I want to, where I was originally meant to go. You know, I feel reasonably secure in that sort of thing.

And if you could somehow, you know, meet yourself when younger, in the room as it were here, or otherwise, what would you say to your younger self now?

Do what you can to help others, because I think other people need far more help than very often given. And I think the voluntary sector, or individuals, are going to have to do far more towards providing some of the answers because they can't come from organisations because the voluntary organisations are being cut money-wise; it's happening all the time. So you've got to keep going, you know. We need people to understand that they can put something in, and that it needn't always be money, it can be part of that person as well. I think that is the main thing. I think people are very money-orientated these days and if they've got money they'll dig in their pockets and they'll give money, which is all very useful but it doesn't solve all the problems. I think sometimes you've got to give party of yourself, which is not money.

And looking back perhaps through things like photographs as we have been earlier on today, you know, the memories of different times, different people, different circumstances must come flooding back to you.

Since I've been doing this actually a whole lot has been coming flooding back. But I really, really appreciate doing it. I said to somebody it's been a great rime. I've really enjoyed it, you know, and I'm still enjoying it. I don't regret the times past, I never had. You can't regret; you can only go forward. And although you might regret, in many ways you never know what's going to happen, and I suppose it's being optimistic but there's always something to look for ward to.

And in wanting to tell people, you know, about your life and things that have happened to you, what do you think is important in wanting to do that?

Satisfaction of being needed and satisfaction of knowing that what you're doing is right. That's it, basically, I mean that's the very basic concept of it. But I think when I was at school there were so many negative things hanging around like you'll never be able to work, you'll never be able to marry, you'll never be able to do this, you'll never be able to do that, and I just think I didn't want the never, I wanted possible. And because I have achieved possible – OK I've never worked, I've not married but I've achieved possible – and that is so much more than being 'you'll never'. I mean, how worthless is 'you'll never'? How much more positive it is to say, 'Ooh, I've done that and I've done a good job.'

And again, if you had the opportunity to those that said then 'never', what would you like to say?

Look I've survived. I'm not the bottom of the class, I've achieved far more than I thought I'd ever achieve and I've enjoyed my life. That is what I'd like to say to them. I think some of them, possibly the ones that I was in contact with, realise this. But there's an awful lot of people I think that don't realise it. But then you can't change everybody's mind and you can't make everybody believe in what you want them to believe in. You've got to be flexible in this world and that's what I hope I am.

And then over the years in meeting people you have in whatever circumstances, what have been some of the things that you've consistently had to explain to people in terms of perhaps people's preconceptions about disability generally?

The fact that I jump around a lot sometimes, with a lot of involuntary movement; people don't always understand that. And it's so difficult to describe because I don't jump around as much as some people do, but I obviously jump around more than most people do. So I've had to explain my disability sometimes to people, which is difficult for them to understand because if you're not disabled then how can you feel what it's like to be in the circumstances that you're in? I still think people think that being disabled must be sad and less now than there used to be but still a few people who can't understand. I mean I've had able-bodied people say to me, 'Oh if we were disabled we'd commit suicide.' And I think, would you really? You know, it would never occur to me to do that; A: because I don't think it's the answer and B: because I have strong enough faith for me not to do something like that, however dreadful I feel, I wouldn't do that. I mean when you go back to the fact that I was only two pound when I was born, I'm here for some reason. And being here for some reason means that I stay here until I'm dead. You know, I don't put me head in the gas oven or kill meself off before my time. Life is infinitely more important to me than that. Mind you I can understand people doing it, but it's not an answer that I would take to.

And in terms of, you know, things yet still to do; what's on the agenda?

Strangely enough; get another carer! [Laughs.] I'm getting desperate. No, get another carer, get life back as it was just over a year ago so that I can do more and – not necessarily do more, but make it easier for me, cos it's been a hard slog. Carry on. If I had a bit more money I'd like to go abroad again, I'm not particularly bothered where I'd rather go, I mean I'd love to got to southern Ireland again, I really would. I've been trying to get there now for about seven years and I haven't got there yet, what with circumstances and one thing and another, but I'd love to go back to southern Ireland. I'd like to go to Rome again. But again, live a day at a time. You know, it's no good wishing for things too much – what'll happen will happen, what doesn't happen won't. It's just a question of living a day at a time, and not dwelling on too

many bad things. If you dwell on too many bad things that begins a downward spiral again, and that's no good, you know. So, yeah, keep going.

And, as well, you know, at various times and in various different circumstances you've had occasion then to meet people who are well-known, famous, including I think, for instance, Cliff Richard?

Yes, I met Cliff very early when we were doing Phab, when Phab was at Devonshire Street [London] – that was the headquarters of National Association of Youth Clubs, of which Phab was one of their links, or one of their pieces. And we did an appeal and it was on television, and I was involved in Phab at that stage and they got me painting on it. And we had a gentleman with brittle bones and Cliff Richard had to say the medical terms for brittle bones and it was really hard, he had to have about four or five takes before he could get his head round [laughs] this long medical word. But he got the word out in the end and we had a lovely time. That was a nice day as well with some good people who... A bit of fun. We all ended up doing disco dancing and enjoying ourselves. I think he was very shy and I think he was very shy of disabled people as well to a certain extent. I mean, some of the other people I've known, like Rolf Harris, not shy at all, came across ever so easily, and the late Honourable Angus Ogilvy was super to me, absolutely wonderful. You ask what one of the things that keep me going, and one of the things that keep me going, I think, is the fact that I've met some people along the pathway of life that have always given me encouragement, and these particular people keep me going. I only have to have a dose of 'em occasionally to keep going because they've always been so positive and they still are so positive, and it's because they're positive that they help me to stay positive.

And, essentially their message in being positive is what?

Keep doing what you're doing. What you're doing's right. And I think you need to be told what you're doing is right cos I don't think every time you get it right. And I think we all need somebody to give us that little bit of extra umph occasionally, and that has kept me going when I've been down. Even when I haven't been down, perhaps when I've been looking for something, it's come along, or the person has come along and said, 'Look, you're doing the right thing.' I've also consistently been

told that I don't do enough for myself; I do too much for other people. I try to address that a bit as well but that's a more difficult one [laughs] to address. I find it awfully hard to address certain things like that. But I've had a happy life and I've enjoyed my life.

And in terms of being known in your community and doing the work you're doing and meeting perhaps different people, meeting including famous people; what does all of that recognition, that awareness feel like?

It's very difficult because if I go out I meet people, and what should be a quick trip up town ends up to be an hour or more because I've met so many people. Or so many people have stopped and said, 'Oh we haven't seen you, are you still doing your meetings?' or are you still doing this or are you still doing that. [Laughs]. Yeah, I mean it's great; it's awfully encouraging to me to carry on doing what I'm doing. Occasionally it has a down side when I think well, you know, occasionally I've said, 'What am I doing it for?' But on the whole it's good.

[End of Track 16]

Tape 10 Side A [Track 17]

It's the 11th of July today then, Dorcas, and I thought we'd start off today then by talking about your memories of Bill Hargreaves – a man within Scope.

I met Bill Hargreaves at Thomas Delarue School, and he was an amazing character. And I remember him telling us that he fell over quite a lot of times, but somehow he always managed to keep upright. He'd got a tremendous personality and gave a lot of encouragement to a lot of people, I think, to do more. I think the people at Delarue didn't need so much encouragement as people that I've met since. I think when you leave school, you lose a lot of the get up and go, and you can get a bit stuck in a rut. I don't think I ever was stuck in a rut [laughs] but I think other people probably have been, because suddenly you're without the support that you've always been given and you're making a life for yourself, and sometimes you're not necessarily developing at the rate that you could do. So Bill was a great character. He used to come and he used to give us all sorts of encouragement about travelling, cos he'd travelled, meeting people (which he obviously had met lots of people) and I think that's what you need. You need to know that you can, that there's people out there that do travel and that do go about; it gives you the incentive to try yourself. It's awfully hard for some people though because some people are too protected by their families who say no, they can't do it, or what's going to happen if this happens. My parents sometimes did that but not very often. I mean I didn't tell my mother that I'd been on a cable car for years after I'd been on one, [laughs] because I knew that if I told her she'd worry about it and I wasn't worried about it. Sometimes you have to do that sort of thing in order to try things out and be adventurous. And I think it does matter who you meet because some people have a profound effect on you even if you don't always acknowledge it. I mean, I get a great deal from people who have helped me, who said, 'We knew you'd do it,' you know, 'We knew you'd manage, we knew this we knew that;' it's great to have that concern because sometimes it feels as if it's something that only you have done. And other people do it as well and I think it's great to know that there's other people out there striving away, it's great to have the support of people and know that what you've done is right, or what they think you've done is right. Because sometimes you just have these little doubts, these little doubts creep in and you think have I done the right thing? Ought I to have set myself these [goals?], ought I to do

these things? So anybody you meet along the way who's helpful, anybody who's got a bit of charisma about them is a definite plus.

And Bill, in visiting you at school of course, he himself had cerebral palsy. So have you at different times in your life drawn other strength from meeting other people with cerebral palsy?

Yes. Not as much as I might have done because of the type of style I live, it's been more me trying to help other people than actually other people helping me. I mean that sounds awful because that sounds as if other people don't help me. Other people do help me but I think when I came home the majority of people needed a push in the right direction in order to do things, and some of them do need a push. You know, I think some people find it very easy to travel along the same road and possibly not to experience friendships and not experience happiness. Whereas that keeps me going.

And, for you, what is your definition of happiness, if you like?

Being reasonably content. But it's not just about being content, it's about achieving things. I think I've been very lucky in my life because I've been very realistic about what I want to achieve. I haven't gone for pie in the sky things because I think that that can destroy so much when you want something that you can't have. It's far better to work round it, you know, to do the things that you know you can do or stand a good chance of doing, and to do them well, than it is to become embittered because you can't do something. Because if you become embittered about not being able to do something, that can take over your life and you can become very resentful about your disability, which is no help to anybody.

And in viewing your life, in thinking about disability, how do you view the impact of your disability, do you believe?

I don't regard myself as that disabled. I know I am but it's not how I see myself, it's how other people see me and that is the disabling thing. A lot of people see disabled as a blanket thing. You know, one person's got it, so's everybody else. I mean I know everybody's got a disability of some kind or other, I don't mean that, but somehow

they tend to put you in a class and unable to break out of that mould that they've got you into, or got any disabled into. And that can be really hard because they never see anybody's potential that way, and it's people's potential that make them less disabled because people say, 'Well, I think I can do that, I'll give it a try,' and they give it a try and find out they can, and it's one more thing that makes them less disabled, and it's one more thing to give them a boost. And people do need boosts, particularly when things go dreadfully wrong as they do. Everybody needs some kind of lift up.

And you described earlier on in your life at school, citing one particular instance where speech day you were encouraged to always think handicapped as it was described – think disabled as we would describe it now. If you had the opportunity to reply to that statement, how would you shape that reply?

Well as I said before, it's a bit negative. One knows one's disabled. But at least I've gone out to prove that although I'm disabled I've got quite a good brain, I'm quite able to think for myself, I'm quite able to reason. If I do have problems it's probably because I've not experienced that kind of set-up before, you know, because never having been in business, [the] business world is a complete new sort of ideas, new sort of way of thinking for me. But you never stop learning, so you learn as you go along. I just wish in some cases there was more help provided when you start off doing things sometimes because you can't get the right sort of information. It's not there. I mean all the people that were good at school like the speech therapist, the occupational therapist, the teacher I had at Croydon, some of the teachers at Delarue, some of the people at John Greenwood and all sorts of people that I've met on the way, have been very, very good. I wish that people would commit to putting some of their thoughts down because their thoughts make such a lot of difference how other people handle you, how outsiders handle you, how people who have never handled disabled people handle you. You know, it matters so much because I think a lot of that is being worn away now and people are having to conform to doing things, and that's not easy because you know your own body and you know what you're scared of and you know what you like, and you know what you dislike, and everybody's being herded towards things like we were mass produced, and we're not mass produced. We're all individuals with individual needs, with individual worries, with individual expectations and everything. You know I sometimes think lumping people together is

not necessarily always the answer. And people now train, but they don't always do the practicalities like getting people undressed and getting them up. I reckon that once you've done that to somebody you can do it to anybody, well most people. But if you've never had the chance to prove it you're never going to know how. You know, I think that everybody has potential – able-bodied people have vast potential – but somehow a lot of the potential is being stifled. And that sort of worries me because a lot of potential is being stifled, a lot of able-bodied people are not growing in knowledge and in understanding, and a lot of disabled people are not growing in knowledge and understanding because they can't see the potential. And it's not just about seeing the potential, it's standing up for what you believe in as well. But it's standing up for what you believe in in a way that you can influence people so that you don't leave them thinking, 'I don't wish to know another disabled person,' cos if you make a mistake people say 'oh that person did that to me'. And they don't think of it as a one-off, they somehow get into a [?] where, if they've been done bad by somebody, everybody's got that same tarnished picture. And it's not true. I mean, this is why I'm awfully careful when I deal with governmental bodies or any body. You've got to realise that, you know, you don't want to give them the wrong impression, you want to give them all the right impression, so that they can move forward. Not so that they turn round and say, 'I don't want to meet disabled people anymore because that person was rude to me,' because not all disabled people are rude, not all disabled people throw wallies, you know, or get upset. I mean, everybody gets upset at some time or other, but it shouldn't be taken that just because you do, or I do, the whole of the disabled spectrum is the same.

And, what have been your perceptions of what is commonly described as discrimination?

I've had quite a lot discriminated in me. [Laughs.] But most of it before there was anything like the Discrimination Act. I mean I've been chucked out of a pub, not because I was in the pub doing any harm, I was only having a drink with me mates, and I mean I can honestly say that we were told that we were upsetting the customers and would we go. We weren't demanded to go but we weren't made welcome and we had to go because we were asked to go. That had a profound effect on me. I thought it [?] to you how misunderstood some people are about disability. I mean we sat round

two very small tables in this pub. There was two wheelchairs, no, possibly three wheelchairs, one or two walking wounded and the rest were able-bodied. And we were literally [at] round two small tables stuck in the corner of this large room with other people. And we weren't doing anything, we weren't making a huge row, and we went out of this pub, went up the road to another local where the pub was quarter the size, the access was practically impossible, and when we told them where we'd come from and what had happened, they carried us all in. And the difference was, well you couldn't imagine a bigger difference, we were really made welcome.

And so what was the explanation as to why you were asked to leave the first pub?

The explanation being that we were upsetting the customers. I don't think we... We might have upset... I think it was just that they couldn't get their heads round the fact that we were having a good time. And I mean, I don't mean an excessive good time, cos the good time was a normal sat in the pub. I mean we weren't making a row or anything; we were just sitting round these very two small tables because it was a big pub, there was plenty of room, but all the tables were round the edges of the room. There was this big space in front of them, a large space in front of them, but we were still asked to leave. It's a bit like when I went to the Holy Land. Somebody was asked very personal questions about her disability. It wasn't cerebral palsy I'm glad to say, it was something, it was a birthmark and a facial disfigurement. And the only reason I can think that they were asked was because of terrorism. But they were asked in such a high-handed way that it made us all feel bad. It made us all feel as if we were fugitives from the law. I mean we weren't, we were just people going abroad to go to the Holy Land. I mean it was nothing [?] about it. I know it was six days before the war that they bombed the Lebanon but even so there was nothing sinister, it was just that when you fill the forms in to get help on the aircraft, the type of questions they want to know are really awful. We moaned about it and they did change the questionnaire but I mean, sometimes they ask such awful things. Things like, 'Have you got a disfigurement?' You know, I dread to think what goes through some people's minds when they ask these questions. I mean, having a disfigurement is bad enough without having to say how you got it, where you got it, what it affects.

This was at, what, entry to the country was it?

Yeah. Well, it wasn't exactly entry to the country, it was partly entry to the country but it was partly so that we could get help getting on board the plane. You know, and that to me is so stupid because I know security has to be maintained, I've nothing against security, but it was the way the questions were phrased, and the sort of answers that you were expected to give in answer to these questions. I mean, you know, I get a bit worried about the Disabled Discrimination Act anyway because I don't know how many disabled people... There is discrimination that takes place which people can't do anything about because they can't afford to fight cases. And it's all very well saying you can get somebody to fight a case, but you've got to find somebody to fight a case and it's not that simple any more. And you've got to be sure that you're going to win otherwise you'll get through a fortune. I mean I know because I've been [there?]. I've used solicitors for all sorts of things because I wanted to be on the right side... in any doubt at all. I'd rather be on the right side than have to explain articles because I haven't done this or that or the other, and the average solicitor doesn't know, which means that he has to go deeper, and then my parents set up a trust so that when they died I had some money. But I mean it didn't make the money last any longer because the money still had to be spent on my care.

And, and in terms of, you know, the reaction of other people? You talked about being in the pub, are there other particular instances that you can point towards where you feel - ?

Yeah. I mean, one of the big ones that I point out in the book – it's quite light-hearted cos I mean I know people do get offended but I try and see it from all sides of view and I think a lot of the time it depends who you're with, how far you take discrimination. But we were going out one day and we were at Knowsley Safari Park and two old ladies passed us by – this is about 25 years ago probably, just about – and we distinctly heard them say, 'Oh those people should never be let out', you know, and it was part of our culture. I don't know what they thought we were, and the two boys who were with me were so disgusted (the two men who were with me), they went and jumped on a tree stump, cos we happened to be by where a lot of trees had been felled for the animals to get round better, and they jumped on this tree stumps, which were sort of not, we were in a walk-through, and pretended to be monkeys.

And then they said, 'Well that'll give them something to think about.' But I mean, it wasn't aimed at them, it was aimed at us as people in wheelchairs enjoying ourselves, because that's what we were. I mean, discrimination can be as blatant as that or it can be very veiled, you know, people say things and you think afterwards. I think one of the biggest things that upset me when I was younger was I won a competition. Not a competition, I won through the heats of the Personality of Northamptonshire for Young People because I was a young person at them time, I hadn't been home very long so I would think about 16, 17, 18, and I got through to the finals. And when I got to London, cos the final was a weekend in London, including a Broadway show. I'd never been to a Broadway show at that stage, and...

So a West End show was it?

Yeah, a West End show. It was *Sweet Charity* with Shirley McClaine in it, so you can tell how long ago it was. And it was also a meal at the Savoy. I mean I've never been in the Savoy, and some – I don't want to say who said it – but some particular person who ought to have known better came up to me and said, 'I don't think it's fair you being here, you have an advantage over everybody else being disabled.'

In what sense did he mean an advantage?

Presumably they thought that the judges were going to favour me because I was disabled rather than because of what I'd done in this competition if you like, not competition, whatever, interview, got through. Hadn't done it for that reason at all. I'd done it because somebody said do it and I thought yes I will because I like to be able to project that disabled people can do these things, and I got through and I was sent to London like the man was that got through. He was able-bodied he was, and he became a very good friend of mine. And he's since died which is very sad because he did a lot for Phab. And I [spent the?] weekend in London. But I was told, more in a sort of veiled way, that I had no right to be there because I was sort of making it harder for the others. And I mean that was not my intention at all and it really upset me because I was still young at that stage. Things like that wouldn't bother me now, I'd just say, 'Oh well, if that's the way they feel, that's the way they feel'. You know. But in those days that was an awful set-back. And it must have had a profound effect,

I can still remember it. I still remember it like yesterday. And I think what was so bad about it was that it was from people who supported Phab, who were quite high up in Phab, having said that. Made me think, 'My goodness, haven't they learnt anything?'

And what was the result of the competition in the event?

Oh, I didn't win. I didn't particularly want to after that. I mean, I don't know. I don't think it upset me to the point where it showed, but it's funny I still remember it and it was the same when my parents were told that because I was disabled, they couldn't adopt anybody. Because they were both given [a] yes and then it came out I was disabled and the answer was, 'No you can't adopt anybody, it won't be fair.' And I thought that was really unfair. And it's funny, you do remember things when discrimination of that sort of nature takes place – you can't forget it.

And in the sense that they were saying it wouldn't be fair, what were the authorities then saying?

That my parents, because they would have to do more for me, would favour me more than another person. And I don't think that's relevant at all cos my mum and dad would have give a lot of love and they would have felt happier me having this brother or sister, than me being on my own. It would have helped my mother tremendously in later years when things got really difficult and it would have stopped all this business about me going into a home, when she wanted me to go into a home and I didn't want to go into a home. You know, which thank goodness I was able to get one or two people on my side who were able to sort of keep me level on that one, because it was the biggest argument I had with my mother.

In that your mother then was worried and wanted you to...

She wanted me to go into a home because she knew I'd be looked after, and she knew that I wouldn't have to worry about anything. And I'm afraid that would have been the easy way out because I didn't want that. I wanted to be part of this world not shut away or put away. I'd had enough of that knowing how things were at school. I didn't

want to go through it again because I've always thought that I could manage, even if life's rocky at times I can still manage.

And, at the time when your parents were applying to adopt, was there ever talk, do you remember, or has there been - [Both speak together.]

They kept... It was when I was school. It was when I was at St Margaret's – no it wasn't, it was just after I went to Delarue...

Had -

... And they never, I mean, mum and dad went through it, and mum and dad came down to see me and told me...

And did -

... because dad was always honest about what went on and he wouldn't tell me but... I'd known ...

And did -

And I was absolutely heartbroken.

[End of Track 17]

Tape 10 Side B [Track 18]

There's been no times when I ever really felt that I was disabled, really disabled, where I felt that my disability was actually a hindrance. Because although my disability can be a hindrance to me doing certain things, my disability needn't necessarily be a hindrance if you're careful what you say and how you say it and who you talk to, and you show people the respect that you would like the respect shown unto you.

And was there ever talk of your parents perhaps having another child themselves?

I think they were too upset. I really think it absolutely shattered them. I think they never talked about it afterwards, they never mentioned it again.

Do you think they, you know, maybe thought to have another birth child, if you like?

Well, I don't know what the woman thought. I'm very sorry that people think disability is a hindrance in things like that because it would have made, and still would make a lot of difference of parents with only one child and that child disabled, because we all need other people.

And over the years, Dorcas, how do you think attitudes, perceptions to disability may have changed?

Oh I think they're much better. I think people are getting the message strongly. But you still get some... I mean, when I joined the Rangers, we used to have people come and pick us up in cars and take us to the meetings. First of all we had a meeting, we used to go have our meetings by post and that, cos that was it was all right but it meant that you had to do the meeting, send the meeting on to the next person, they did it, they sent it on to the next person then eventually it would get back to the person in charge, they would correct it and send the next one out. And we decided that, as things were moving that rather than get our meetings by post for Rangers, we'd like to meet and so we started meeting once and we used a lot of voluntary transport. And I remember when I lived in Midland Road going to a meeting and the man was

absolutely petrified. He made my uncle come as well because he was so sure that I was going to bite and scratch and I couldn't make him feel any more comfortable. He was that petrified, uncle had to go with him. He brought uncle back, picked uncle up again, went over and picked me up and brought me and uncle back again.

And how old would you be at this time approximately?

Well I'd got to be in my twenties. Late twenties I would be, middle to late twenties, which OK it's a while ago, but it's not that long ago, it's not as long as the other incidents I've talked about.

And when you had meetings by post, it was a sort of newsletter was it and you added your own news to it?

Well, you got asked to do certain things. You know, you had to talk about your life and you had to do certain things which meant that you could eventually pass. It was very well organised, it was very good but, I mean, by that time I was camping anyway and I knew there was so much more than just having meetings by post. And when it became possible to meet monthly we met monthly and it was really good. I mean we met monthly for quite a long time until we disbanded.

And so throughout your life so far then you've had a determination have you, wherever possible, to take part in things, to be out and about if you like?

Oh very much so. That's the whole of the Phab philosophy. I mean Phab was meant to start people off on the right track, and they were meant to go and belong to things and do things. Phab was not meant to provide totally long term answers. Unfortunately people have not been able to move on so Phab is still going because people still need it and people with multiple disabilities find it even more difficult to move on.

And for somebody who, you know, if you meet somebody as it were in the street or wherever, somebody who hasn't had any contact with anybody with disability before, what are the kinds of messages that you're wanting to get across to that person?

It depends how long you're with that person for. I mean, I can get an awful lot across at meetings and things like that – I don't mean structured meetings but I mean old age pension meetings, that sort of thing – I can get an awful lot across just by being there sometimes, and just by proving that I've got brains, that my brain's working and me brain's ticking and I'm providing some of the answers if you like. But, having said that, there's all sorts of people out there and there's some people that you just can't reach because their prejudices and their difficulties are so deeply entrenched that they won't see you for what you are no matter what you try and do. The biggest problem, I feel, is language. Cos people use the language they know. They don't necessarily use the most up to date. I mean, to some people being 'handicapped' is still a normal word. And to a lot of older people it's still a normal word. And you start saying modern language to them and they won't know what the heck you're on about. They won't know that being differently abled is an American thing where you're supposed to have overcome the word 'handicapped'. They won't even, you know, I mean it takes along time for language to die. It's taken an awful long time to get rid of the word cripple, and I daresay it'll take an awful long time to get rid of the word spastic as well. Scope, I mean, that hasn't gone yet.

The word spastic?

You know, I mean it's going because it's no longer the official language but people still say spastic because it's what they're brought up on. I've got a friend who still says handicap. And he's a lovely man, absolutely first class man. He understands my disability perfectly. Great person, great friend of mine, but I can't get him to change his language.

And so, in your choice of language, what are the preferred sorts of words that you yourself would prefer?

Whatever people feel comfortable with. I mean, I do think that some of these organisations go over the top, and I do think sometimes, I mean, I don't like the word 'user'. It makes me feel used anyway and although I want to be useful, that is not the same as being used. Used makes me feel crummy. You know, it makes me feel as if I'm...

This is in the sort of instance where people say the word 'service user' for instance?

Yeah. Well, I'd much rather be a client or even a patient than I'd be a user, and be used, because used is the wrong word. Unfortunately it's a word that came into being, particularly around here, because people with learning difficulties couldn't understand other words. And the social care team use 'use' and 'user' a lot and it became the accepted language, and that is one word that I bitterly regret because I don't think it does disabled people a favour at all!

And so the words 'disabled people' in preference to 'people with disabilities'?

Well, anyway, whichever way you look at it. I mean, I use people with disabilities, but people still don't use that expression to me. You know, and I do try and think about it but it's how many people react to you that make a difference. You know, you've got to react to people at the level that they'll understand what you're on about. You can't react to people with a whole lot of gobbledegook that they know nothing... I mean, it's not gobbledegook to you and it's not gobbledegook to me, but it is to them. And if you're trying to get people to understand, the last thing they want is a whole load of language which they don't know anything about.

And, again, over the years, in terms of your different feelings at different times, how do you believe that your own perception of yourself may have changed over the years?

Oh it has, but it inevitably would because you grow up and you cope with things. I need to keep going. I need to keep going so that when I hit bad patches I can go through them. Because the worst thing about a bad patch is thinking about it, and if you've got too much on you think about things and that is that. It's all right to think about good things, but it's not so good to think about bad things.

And what gave you that kind of outlook really?

Parents, inevitably. I think in certainty that I feel comfortable doing it. If I didn't feel comfortable doing it I wouldn't do it. But it has given me an awful lot in my life because what you sow you reap a hundred times over. And so I've had some wonderful friendships; I've been to some wonderful places; I've done some wonderful things. I have no regrets, and that is what I think keeps me on going, keeps me ticking because I have things to look forward to. I don't have to sit in the same [place?] without anything to hang on to without any hope or anything. I do sit indoors some days, but I know that I'm going to do something else, I'm going to be more, I'm going to go to Westminster tomorrow or I'm going to go camping or I'm going to do something. And even if I don't get there it's still something to keep the brain ticking, to keep saying, 'When I get there I'll help so and so,' or, 'When I get there I'll do this,' or 'When I get there I'm there for whatever need arises'. You know, I mean, it could be that next week they'll want a lot of help, it could be for next week they won't, and I'll just carry on, you know, without poking me nose in and doing – I don't mean poking me nose in – but without giving any guidance or anything...

This is -

... you know, cos you can have a good week. I mean, usually different problems happen in different years. It's sometimes down to the mix of people with disabilities, it's down to the mix of able-bodied people, how they react, how they feel, if they feel comfortable then everybody else feels comfortable, how tired we all get, how we cope with the stairs, you know, It's a hundred and one different things.

This is next week, the annual Westminster Phab residential activity week. How many years than have you been going to the Westminster week?

I think this is 29 and I've been going to 28 of them. I'm sure it's 29 this year. You lose track after it's been a while. [Laughs.] I mean, it was wonderful cos dad and mum were alive when it started and they was very well, very happy for me to be involved. Happy because they knew I enjoyed it and happy because they could see what the end product was; that people enjoyed it, that we were giving something to people what they might not otherwise have, which is always important. So many of

them it is their one week of the year and that is very important to people. People should be able to have pleasure one week a year at least. [Laughs.]

The week assisted by students from Westminster School in London.

Yeah.

And what are some of the particular favourite activities that you have done and will do for the week?

I like doing art, but I do anything now. If there's a shortage anywhere I get asked to go so I never make my mind up. I have done art several times and I do like doing art, but I know that if I do art I'm very lucky, but art is a thing that quite a lot of people can do at Westminster and it can be quite a large group whereas some of the other groups aren't quite so large. So I go wherever I'm... If they're a bit stuck I float to another group. I've done everything. I've only done drama once, I've done dance, I've done music, I did music last – no, yeah, last year, or was it the year before? Year before. No, last year. I've done video, which I enjoy very much; I've done writing a report of the week, which was dead easy. I've done all sorts of things. You know, I don't mind. I say to Andrew, I'm one of the last people that makes a last-minute choice about anything.

And in doing art – painting particularly perhaps – how do you paint?

I paint with a brush held in my mouth, which is different from how I did it at school cos I did it with my hands at school, but I love painting, well, for most of school but not all of school I did bits. I love mixing colours and seeing how many colours I can get on a piece of paper. I like doing things like stained glass windows and that sort of thing. And I get a great satisfaction out of painting and it gives me a lot of pleasure. And the great advantage of doing it on a course like that is you don't have to clear up. Clearing up can be such a problem. You know, when I'm here it's not something I do now because, you know, there's other pressures when you're at home. When you're on a weeks course you can, it's part of the course and you just do it. I mean, I don't stop, I work solid.

And in working, you know, or being assisted by and enjoying things alongside these students from Westminster School; over the years how do you think their, or have you perceived changes, in the kinds of questions that they will ask?

It sounds awfully pompous what I'm going to say but there's some very intelligent people, and they always get more people than they need, and they go to a session and see the most suitable people. Some of them do it twice but mostly not. They only do it twice if they come back and be a tutor or if there's a special reason for them to come and do it twice. And I always find it greatly encouraging because they're still at school they're still learning and they're still into learning. And because they're still into learning it's fascinating what you can find out. You can have a talk about all sorts of things, about what they think about disability to how they think they'd solve it, what they're going to do, if they're going to be doctors, nurses, teachers, whatever. Quite a number of them have become doctors, particularly the ones that have done Phab, and I think it set them off on the right sort of path.

And, what do they think of disability typically? How has that changed?

It's a great culture shock. I mean, they've never done it before. But, I mean, I can always explain my disability and I can always explain what I need. Some of the disabled find it a bit difficult doing that, but there's always people around that can sort of sort round it or sort it out. Yes it is hard work, it is tiring but then you expect it to be because it's an action-packed few days. And it is action-packed so that A: we get the most out of it and B: the people helping us don't get bored. I've never got bored; I don't know what boredom is. I wish I did sometimes.

And, yes, as one year follows another, how do you believe that, for you, the circumstance of your own cerebral palsy has that changed?

Not an awful lot. I think the thing that changed most is the fact that I had the hip removed. I think that's what changed; my physical ability. I suppose as you get older you get less things that you can do easily, but I've been very lucky – apart from the hip which was a real bind and still is – I think I'm pretty much the same as what I always

was. I don't think I've deteriorated. I've deteriorated somewhat but not to a great degree. I can still relax. I find relaxing very hard but on the other hand I don't move about an awful [lot?], I don't move about possibly as much as I did, because I've learnt to relax. I mean to somebody who doesn't move about at all I suppose I do move about a lot, but it's not obvious to me.

And again, so far, what do you believe has been your greatest achievement, or among your greatest achievements?

Having friends. Definitely having certain, you know, I mean, having friends with the kind of upbringing that I was told that I would never marry and never work, which kind of destroys the way you think sometimes, and I've managed – I don't work, and I don't have a husband and I'm not married, but I'm happy. And I think that's the biggest achievement because all the odds were stacked against me. Leaving school early was stacked against me. Well not early because I was over 16, but leaving school as early as I did was stacked against me. Not going to college like some of the other people was stacked against me. But I've never regretted the road I chose to take.

Yeah. And, you know, what drives you on, as it were? What keeps you happy?

Again friends, reading a good book, being useful. I think so many people with disabilities lose a lot by not having an interest. You know, it's so easy to say, 'Oh I'm not going to do this or I'm not going to do that.' It's much easier, but in actual fact if you do do things it widens your horizon terrifically, and you find that you can cope with things that you might not have coped with had you not tried.

And, again, sort of over the years as it were, what contact have you had with the Spastics Society as it was, and Scope as it now is?

Not so much I don't think. I think one time at the Louvre really shattered my... I mean I met some wonderful people but I also had quite a difficult time and my father was involved with the local group, so when he was alive I was kept in touch with what was going on. I don't go on many of the outings, not because I haven't had the opportunity, I mean I get the newsletter, I can go and do whatever I want. I think

sometimes a lot of it is because I've done so much and so many people haven't, and OK you can share information with some people, but there's some people that you can't share information with because they don't like that. And, you know, I have a lot of time with all the other things I do.

And, and in writing the [coughs], excuse me, in writing the booklets that you've written and in publishing those; what has been the aim of that?

Really to make more people aware, and to do whatever. I mean, I think people need to know because I think in the past disability has tended to be put a person away and forget about them, whereas now it's not put a person away; a person's a person. A person has a right to live the same as anybody else, exactly the same as anybody else; with help. And I feel that so many people get this confused with disability and think that you can't do things when you can.

And, in terms of the things that you'd still like to do and plan to, hope to do; what is on that list?

Well camping's always on the list because that's where I got most of my friends from because I've been going so long, and because again I feel useful when I go, and because I like to help people as much as they help me. And that includes people with disabilities and people without disabilities. It gives me a chance to recharge my batteries cos it gets me out of Wellingborough, which is OK for 99 percent of the year but I still like to go away occasionally, well more than occasionally, and recharge my batteries somewhere else. And it's funny, while you're working like frantic fury, somewhere like camp helping people; it still recharges your batteries because it's somewhere completely different. And the same applies to Westminster Phab residential course – you never know what's going to happen; you have to keep your wits about you, you know. I mean, I try and keep my wits about me all the time if I can, just looking, not appearing to look but looking just the same, if you see what I mean. [Laughs]. And, and making sure that everybody's all right, and if it's not I say something to somebody or we talk, I talk about it to Adrian or one of the other staff members and we discuss it and I can do that, and that is the advantage of having gone so many times. And also having done camp a lot of times as well, my mind and my

body are attuned to when things might not be going right with certain people and when certain people are not particularly enjoying themselves. I might not always know the reason why they're not enjoying themselves but I can always, I bet your bottom boots, pick them out that they're not enjoying themselves. You know, it's something that when you've had a lot of occasions with a lot of different people, you get a second nature about these things and you realise what the problems are sometimes, whereas other people might not.

[End of Track 18]

Tape 11 Side A [Track 19]

And one person, Dorcas, that you came across I believe in connection with the Spastics Society (as it then was) was a lady called Margaret Morgan. What contact did you have with Margaret?

Well, she again was a visitor from headquarters, as you might say, but she was a very qualified person in a very unqualified situation. [Laughs.] You could talk to her and you felt comfortable with her and I think she never appeared alarming, she always appeared easy to talk to and easy to put your views over, and encouraging. And she'd got a memory like the queen mother, cos the queen mother has got a phenomenal memory; once she met you she remembered she'd met you. I mean, OK they might have to read up what they're going to do before they go on a journey to meet people, but it is so nice when people recognise you years afterwards and it means that you've had some impact in their thinking and they've certainly had impact in your thinking, and I think that is very special because it means that somebody somewhere sees the qualities in you even if you don't see the qualities in yourself. And I think that's important as well. And Margaret Morgan had this special quality of, I think, being able to relate to people, even if they weren't always or didn't always appear as successful as some of the other people that she met. I mean, when we were at Delarue, because we were secondary mod at the bottom, I mean, we didn't shine like some of the students that were doing O-level or A-level, and yet Margaret Morgan never made that a division. She was the same with everybody. And I think, I can't say that about everybody who was at the school. I can say it more about the people that actually physically looked after us, they were more or less the same to everybody. But the people who actually had to make decisions and were somewhat choosy.

And Margaret's role, what was her precise role in so far as she had contact with you?

I don't know. She used to come down, give advice, and I can't recollect when I first met her, I only know that she talked to us and that in years later I was impressed with her. I've always been impressed with her and I think the reason she impressed me was because she was the same every time you met her. She wasn't somebody who changed because of certain conditions in yourself changed, or she wasn't somebody

who made you out to be something that you were or weren't. She was somebody who was just totally natural.

And so she was offering advice and assessing -

Yeah. And certainly when I met her later she was very encouraging. And, I mean, my parents were my first encouragement when I got home from school, but I still needed other people to be encouraging as well. More so than I do now. Because I think when you're starting off on life's journey, you do need more help to start off, sometimes just to give you a bit of a confidence boost. And over the years I think I've got more determination and more set in the ways I'm going, and I'm very glad I have because that's led me to be mostly fulfilled.

And this is perhaps in some ways an unfair question really in the sense of its size, but across the years what are some of the memories that really stick out, really come to mind?

Oh, lots of things. Having the Toc H [a community-based charity] come and give us walks when I was at school because we didn't have that many outsiders at Delarue and that, and Delarue was along way from town.

Did they give you talks?

No, walks.

Walks.

They took us up and down the road which, when you didn't go out very often was quite a nice treat, and it was also nice to meet able-bodied people from outside, because we were miles away from town centre. We didn't meet that many able-bodied people and to me it's always been most important that you meet people, whoever they are, and whatever they are, and however they think, it's still important to meet people. I used to relish that. I mean, we knew what the walks were going to be cos there was only two ways you could go: up the road or down the road, and we didn't go that far.

But it was so nice of these men to come and spend a Saturday or Sunday afternoon to take us out. I mean ...

And so these -

We didn't go very often because there was quite a lot of us, and there weren't that many men.

And so these were people then who belonged to the Toc H organisation?

Yeah.

And -

And who had discovered that we needed to go out. They couldn't take us out in cars cos they probably hadn't got cars in the days that I'm talking about, but they could push us up and down the country road, and we used to go out like that, you know, and that meant a terrific amount to me. Camping at Woodlarks means a terrific amount to me cos, as I said, that's where I've mostly made all my friends. Going back in time, some of the places I've been – Paris, Rome, lovely places – that gives me a tremendous kick, you know, and at least if I never go back I've done it. I've been [to Rome]. I love the place, I love the feel of the place, I love Rome because I'm interested in Roman history and Rome just fascinates me. Paris I think is wonderful though. I've got a good friend who lives near Paris anyway, which I always try and see when I go to Paris. But, yeah, wonderful, both exciting places and both wonderful places to visit. I love my culture. This is why I like going to London. You know, I love going to the theatre, I love going to the National Gallery. Art means a great deal to me, I spend a lot of money on art, I mean, last night in bed – I hadn't got John here cos John only came this morning – I had to ask my carer who only puts me into bed and gets me up when John's not here; I asked her to come at 10 o'clock so that I could watch *A Picture of Britain* with David Dimbleby. I really enjoyed that, and I really enjoyed Dan Cruickshank's *Eighty Great Treasures* and I didn't see all of them, but what I did see I enjoyed immensely. I love seeing paintings that I've never seen before. I love art books, I like reading, so, you know, I'm quite a cultured person in

that respect. I also like reading about people with disabilities as well. But I think I do, although when I'm at camp and when I'm at Westminster I'm helping both, I think, over the years I've helped possibly more able-bodied people than I have disabled. I'm never quite sure why, but I suppose it's the way the cookie crumbles. Going to southern Ireland was for me one of the most magical experiences. I don't understand why particularly, but it was. I'd love to go back. I keep promising myself I will. The trip a few years ago to St Ives to see this school, going up St Ives you know, going round the caves at St Ives, learning about Alfred Wallis, you know, everything, that was good as well. Going to Canada was brilliant. So yeah, there's been lots and lots of things that keep me fired up and keep me going, and if I give talks I vary what I say to them quite a lot, cos there's quite a lot that I can vary. So that, if I go back to the place and do the thing again, they still hear different things. And I think that's why, you know, they ask me back.

And so what kind of ground do you cover then in your talks, particularly recently?

Where I've been, what I've enjoyed, what's less enjoyable like people patting me on the head, you know, things that people can relate to because I think if people can relate to what you're saying, you get so much better and it really does being to mean something to people. I think if you talk a whole load of gobbledegook, nobody wants to know.

So you've had people literally pat you on the head, have you?

Oh yeah, they do. Quite a normal – [laughs] it's not normal but to them it is normal. I mean, a dear friend, an absolutely dear man who I love, an immensely great man; always patting me. I can't stand it but, I mean when it's somebody that you know and you know that they don't mean it, it's just that you're at a convenient height, and they just do it without thinking what they're doing it on, you can't very well turn round and say, 'Please don't do that,' because that would have upset him.

And another circumstance which sometimes people describe is, in a sense, where perhaps you're out in the streets and with a friend or with a neighbour and people will talk to your friend or your neighbour and not to you.

Oh frequently, frequently, they still do that. I mean I went out a few weeks ago with my good friend Julia; well we went on this year's Mother's Day cos her son wasn't able to get back. She'd booked a table and there was one spare seat so she asked me to go because she knew John wasn't here and that I'd enjoy a meal out, and she took me out. The woman there – the boss... We moaned because we rang them up and asked them to put the ramps out and they didn't, so they had to fiddle and get them out. We got up the steps because they were waiting for us to be seated, but coming out we asked for the ramps and this woman was really, really patronising, horribly patronising. She said, 'There, don't worry dear, everything will be all right dear'; I was nearly throttling her! If anybody could have seen it I'd got smoke coming out of my ears. Julia was absolutely furious cos she knows immediately when I look... And my friend got a weekend job there. She was furious as well. That is what I call really patronising, and that was this year.

And where does that kind of reaction, kind of attitude stem from? Where does it come from?

I think it comes from not knowing disabled people, and I suppose because we'd moaned because the ramps weren't down, she thought she'd got to be extra nice. But she was over extra nice, she was absolutely pathetic. Because I've been up and down hundreds of ramps in my time, I don't need that kind of security. I wasn't scared about going down the ramp. When I ask for things like that it's not normally because I'm scared about going down ramps or anything, it's to make it easier for other people because other people will go in that place and if a ramp's not there, will just as easily walk out again. Or they might not even say, 'Look, where's the ramp?'

And again, around and about, what kind of changes in access circumstances have you noticed?

Oh I've made lots of changes in access, cos that is my forte. I enjoy access immensely. A lot of dropped kerbs. They're not... I do understand about them all having little lips because of people who can't feel the edge, but the more dropped kerbs I can get in a place the easier it is to get round in it. I mean, it's about

understanding; it's about this word reasonable. Barbara, the access officer who does Ability Northants (cos we do our own access audits and things like that), she relies a lot on 'reasonable' because she says how can you expect a shop that perhaps is a one-man business-type shop, to make all the changes necessary when perhaps they don't even get any disabled people going to that shop. You've got to be reasonable about actual [?], whatever reasonable is, and I'm not sure I know what 'reasonable' is. But you've got to understand that some people just cannot do what they want to do.

And this is 'reasonable' as now called for by the law?

Yes, yes. Because you can't make anybody do anything. That applies to everything. I can't make my carers do certain things – if they don't want to do them I can't make them. I can't make access in Wellingborough if somebody doesn't want to do it or doesn't want to know. I'm not going to make any difference. I'm going to try and I'm going to have a jolly good try, but you have to realise that these things are not going to happen just like that in a puff of smoke, they take their time and you've got to have time, and you've got to be prepared for people to do their best and you to do their best. I find that I get a lot done because of the way I ask. That is so important. If you want to change the world you don't change the world by being a bull in a china shop, you change the world by moving one grain of sand at a time.

And in a sense of course that the Disability Discrimination Act calls for reasonable adjustments to premises and other circumstance, under the Disability Discrimination Act. And you referred there to Ability Northants. What is the role of the organisation?

An umbrella group and a friendly person at the end of the phone that can point people in the right direction as well as keep an eye on what's going on, what's the health and social care sort of decisions coming out of there, what sort of decisions are coming out of government, what sort of decisions are coming out of county council. Because one of the biggest single issues is people not asking disabled people, or people with a disability as you put it, not asking them what it's like to be disabled. People haven't got a clue what it's like to be disabled. They can't begin to understand. I mean Mr Blair can say oh I'll make this possible, I'll make that possible, but he can't know what it's like at the bottom, begin disabled, of having a disability and coping with it.

Nobody does, only the person concerned knows that. You know, you can try and make people more aware, but when the bottom line comes to it you are the only person that knows. Because everybody's disability is different, and so you can't really make mass assumptions, you can only make assumptions on how things affect you, but on top of that, everybody's so afraid of being sued these days that is really becoming quite frightening. It's quite frightening that people can't do things in the way that is best for them, they have to do things in the way of health and safety and that sort of thing, which is really a pain in the neck at times, because nobody knows what it's like and people try and force you into corners where you don't want to go. They wouldn't go in them if they were in the same situation, but they force us to go in them. And that is why it's so important that people understand better about what it's like to have and to live with a disability.

And how do you think that your understanding of disability generally, and perhaps your understanding of your own disability, has that changed from when you were younger?

It does change because you learn more. I still wish there were more people that were around that give advice, legal advice, because I still think people are advised to do things, like go into homes and things like that when they don't necessarily want to, because there is so little alternatives – unless you're really determined and you really know what you're doing. You know, and I'm sure that there's a lot of almost disgruntled disabled people who have not fulfilled their potential, who regret being disabled because they haven't been able to fulfil their potential. And that's sad because that's almost like a waste of a life. I was taught, and I still firmly believe, that we're all here for a purpose, and so I'm going to prove what my purpose is, thank you very much. You know, I think I am here for a purpose and I'm going to always keep that in the forefront of my mind, because that's important to me.

And what do you believe your purpose is?

To encourage people to see that we're not so different – we are the same. And if more people understood that then more things would become equal and there would be less diversity amongst people and more understanding and more equality and more help

and everything would become a lot easier, because it does. If you know people you can talk to people about things, they'll talk to you about what their fears are and you can meet them on the same terms. But if you don't know what anybody's getting their knickers is a twist about or got a fear about, you can't help them. It has to be a two-way process, and that is so very important, and it's more important now than ever before. I'll tell you why it's more important because with medical science advancing the way it is, it's important that people with multiple disabilities are given as equal chance as those with less disabling issues. Because everybody is here for a purpose.

Yeah. And each day is a new day. When you begin a new day, what are the some of the thoughts that come to you?

When I begin a new day, first thing I say when I wake up is, 'It's going to be good day today'. And it doesn't matter if it's a good day or bad day; it puts you in the right frame of mind. You haven't got up saying, 'Oh it's going to be a bad day, I'm going to have an awful day,' you've got up saying, 'I'm going to have a good day.' It makes it more positive from the start. It isn't always so cos good days can turn into diabolical days but because I know so many people, I get far more concerned about other people than I do about myself and that in a sense helps keep me going as well. Because you're thinking about people like I was thinking about you on Thursday down in London. I was thinking I hope Philip's all right, you know, even though I was rushing around here like... I mean, we got home at half past 10 Thursday night because the meeting didn't finish while half nine, it's an hour from [?], you know, so we had quite a full day on Thursday, but it didn't stop me thinking. I think most of the time I think I don't very often have a blank mind, because I'm not made like that.

This is Thursday when there were bombs in London. And in terms of being able to contact people, being able to get information, what kind of difference has the computer made to your life?

The computer's wonderful because it means that it's so much easier than a typewriter was, and I can get in touch with people on a day-to-day basis. When I'm away I don't miss it though because when I'm away I've got other things to occupy my time and my energies and my abilities and what have you. But when I'm here I like my computer;

my computer's a good friend, because it lets me talk to people like my friend in Australia who I've known for 30 plus years through camp, and we correspond on a daily basis, which otherwise I wouldn't be able to do because I couldn't get anybody to come here and write for me every day. It's also nice because I can put photos on, look at photos, contact various organisations, do quizzes and things that give me pleasure what I've never been able to do before, cos I like to keep my brain ticking over and active. And I suppose it's given me a new lease of life in a different direction. It's far more rewarding than the typewriter ever was. The typewriter was OK for putting things down but it was a messy sort of thing, whereas the computer isn't messy. It's annoying when it goes wrong. At the moment we're thinking about going wireless. Because John uses my laptop when I... cos I use this one when I can. But I've got a laptop in case anything goes wrong and he uses the laptop. John's my carer. He uses the laptop. Pay and go is rather expensive so we're looking at alternative ways so that way we can go both on to Broadband and it wouldn't be so expensive. The only thing is it's the initial layout and the bits that you require to make it possible, but we'll get there in the end.

[End of Track 19]

Tape 12 Side A [Track 20]

Here we are today, Dorcas, on the Friday the 20th of January, 2006, and we thought we'd start off then talking about the experience of independent living or living independently. Now just describe to us if you would, how for you then that came about.

Well I had community service volunteers, and they were changed every six months, and I had them for about five years and I – no, less than that – but I had 25 different people in quite a short space of time. And I still wanted to live independently because, being the sort of person I am, which is a doing person... [Telephone rings.] Yeah, so I got through 25 helpers in a short space of time and community service volunteers were finding it more difficult to get the helpers to cover the people cos I had to have two to cover the whole of the week – one on and one off – and their organiser (who I got to know quite well as you can imagine) doing all this, said, 'Why don't you go to Independent Living?' So I went to Independent Living and got the money out of them...

So when you say you went to Independent Living, was this then the Independent Living Fund or...?

Yeah, the Independent Living Fund. I got the money through them and had Independent Living right until Mum died, and then I came into my own money.

So the Independent Living...

They couldn't help me any more, so I then thought well... When I started paying for my own care, which in a sense was more realistic because I could give them proper money rather than amounts which were doled out. Because Independent Living Fund was administered not by me actually. It was sent to my solicitors who then gave me so much money to live on.

So the Independent Living -

So I was in charge of the money, I mean I could ask for it, it just was a bit of a [?] step. I mean I got to know what I was doing and the solicitors made sure that it was all legal and everything, so I felt perfectly safe really. I wasn't required to do anything, only to get the money out on a monthly basis.

So just to explain about the Independent Living Fund then; government derived money, was it, and...?

Yeah. Well then after mum died and I'd spent the money I had to go back. And my social worker, because I had to go back to social workers – I'd never really left them cos they kept coming. I'm not quite sure why they came in certain circumstances; I think they got confused, I think they still thought that I was on Independent... I don't think anybody had ever said that I'd stopped, even though I'd stopped getting the money, if you see what I mean. So they checked me once a year. A bit of a waste of time really. And then when I went to get back on the system, the social worker I was assigned then said, 'Oh, we don't think we can get Independent Living Fund because you need full 24 hour care. Independent Living Fund won't pay that sort of money.' So I couldn't go back on that scheme, so that was when I went to Direct Payments, and I was one of the first at that stage in the county to do it.

What do we mean by Direct Payments?

The County Council pay you a set amount of money which is negotiated according to your needs and it's called Direct Payments, it is paid by the County Council and government instruct that this is the way forward they want things to go, so consequently you go forward like that, and they pay the money monthly, the support agency has been Independent Choices which was based at [?], and I've just heard that it's changed.

So there's a pot of money then, or an amount of money that comes from the County Council that would otherwise be spent on services but is given to you, to in turn employ people and buy your own services...

Yeah.

... through this other agency –

Yeah.

administered by this other agency?

Oh no. You get sent the money, it's up to you how you spend it, but you have to provide all the returns, you have to pay the tax. And unfortunately tax equates for a third of the money that I'm supplied with. I mean it's well, in December it was £1,000, which [?] tax and leaves only 2,000 to pay the wages.

So you're in a situation then of employing people...

Yeah.

... with that money to account for your care needs. And do you get advice then in terms of the employment of carers and personal assistants?

I'm afraid I had to learn the hard way. That's probably me. When they set it up, it was still very new and I think the goal posts have moved so many times since then. They've certainly tightened the scheme, tightened it considerably. By tighten I mean you now have to prove that you've paid that because somebody had the [money?] and spent it on themselves. And it only takes one person to do that and the whole caboodle's at risk. So now I have to provide returns. If I get too much money in the pot left over because somebody has gone on sick, I have to return the money, which is not really good because I have to cover holiday time. I mean I don't get increase for holiday, and in fact when it first started the contract said that carers couldn't get paid when they were on holiday, which is [?]. It contravenes the laws and what have you. You have to pay carers, you have to pay replacements, and I think because the pay is so pathetic, it's so hard to get people. And I don't want to shout too hard because, I do want to shout and make a fuss, I understand that a lot of other people feel the same as I do, but although you're encouraged to say what your problems are with the scheme, nobody's going to give you any more money.

And so in deciding to opt for this arrangement and to have Direct Payments, you were saying that you were one of the first in Northamptonshire to...

One of the first.

... One of the first. What made you decide that you wanted to pursue this route?

Because I wanted to live independently. Because I can do far more being independent than ever I could if I was in a home. Because my mind is always alert and I've had a lot of experience with people with disabilities or people with problems to know that if I go anywhere people expect me to wave my magic wand, and I don't want to be doing that on a regular basis. I don't mind doing it where I can see that I'm going to get somewhere, but if I'm going to be overloaded like that I don't want to be overloaded like that. I still want my freedom, I'm still able to enjoy life and enjoy life to the full, even with its problems. And one of the biggest things I faced when I came home was jealousy from other people. It's the most negative thing you could ever get, it really is, and it almost completely destroyed me. And it was by people who were disabled themselves, who couldn't see a way forward, and who were just jealous because I did things. I saw the way forward and got there.

So what were they jealous of then, particularly?

Pardon?

What were they jealous of in particular?

The fact that I went on holiday, the fact that I was able to organise my life, that they couldn't see that they could. And those people are still around and it makes me very hesitant. I've done lay assessing in homes; I've done all sorts of things in homes. I know what the current residential situation is like, and it's not for me.

And so when did you first go on to Direct Payments then?

Five, five or six years ago. Six years ago. Maybe. No, seven years ago.

And in going on that scheme then, did you at that time join with other disabled people to work out the best method...?

No, there was nothing like that. There was just nothing. And that has only just come about in the last year. You could always ring somebody but I am not very good at ringing people, and I'd certainly rather learn about things myself. And I certainly feel much more independent, the fact that I've got my own person who does the wages for me, who provides the slips, I've got my own solicitor, I've got my own thinking processes. And I think with money getting tighter these things are getting tighter and tighter which means that people are seeking more and more help.

And so the money you're getting then, that's allocated at particular times, but how does that then compare with the costs as they now are?

Not very good really. I mean, taking the fact that I pay all that out for tax and national insurance; it would be nine pounds an hour with tax and national insurance included. It's less; it's just over six pounds an hour, which is not good. And sometimes, I mean it has been as low as just the minimum wage. It's only the fact that they do 24 hours on shift... I mean OK it's better than what some people get, but it still puts a lot of people off doing it because it just isn't good money these days.

And so in terms of, you know, your own circumstance and going about getting this method of payment and getting what you need, what kind of difference made to you in terms of your...

It means that I'm down to a savings of £2,500, plus my pension. Because having more means that I don't get as much pension. [Laughs.] And that's a bit stupid as well because it works out that for every 250 you get over 3,000, you have to pay a pound back to the government which is... So I'd rather... It means that I do have, if anything big comes up, I do have to work round things but I mean, it means I have to think, particularly at the end of the month cos all the bills come at the beginning of the month basically. So the end of the month's always a bit more trying than the

beginning of the month. Yes it makes you money conscious but it's very important to live independently to see all these problems because in seeing the problems you understand a lot – I understand a lot more about things and I've got answers for things whereas if I hadn't have done it and somebody had done it all for me I wouldn't have the answers. But I can quite see why a lot of disabled people don't want to face up to doing it.

So what would you say then to somebody thinking of pursuing the same route?

I'd encourage them but I think a lot of them would fall by the wayside because it is so complicated and because there's still this [?] about people being cared for. I'm cared for but I'm certainly my own boss. I mean, I don't mean that horribly, I mean I'm not strict or anything like that, they can go and do what they want so long as they tell me. You know, I mean, I'm not going to stand behind them with a big whip because I couldn't do that anyway.

And in terms of being your own boss and being independent; what difference does that make to you in terms of your daily life?

A heck of a lot. I mean it means I can do all the things I enjoy doing. I mean I can help the community far more by being independent than ever I would by being in a home. All I would be helping would be the people in that home possible, and they would never understand why I go to all the meetings that I go to and why I get involved in the things that I get involved with. Being my own boss means that I don't have to necessarily explain to anybody why I do it.

And in -

And doing it gives me great satisfaction.

And in, you know, discussions (if they were ever had) in looking forward to the time now, was it ever predicted or what were the sort of assumptions that you might have been discussing really?

Well, I mean my parents both thought I'd go into a home, when I knew that I wasn't going to go into a home. It was the biggest single argument with my mother. I don't think it was so bad with my dad. I think one of the biggest problems, if you like, was the fact that they couldn't see me in any other situation. My dad could but my mum couldn't and I think the biggest problem was they'd been brought up in the sort of era where people put people in homes. Back in the sixties you could appeal for things and get things a lot easier than you can now. I mean, it's a lot harder to get things because we're going backwards a bit in that sort of respect. People don't seem to realise that people in this country need things. Pensioners need things. Disabled people need things. And I think a lot of disabled people give up at the first hurdle.

So this is in terms of, you know, the amount of just money around for things like social services and other provision. You feel that money is tighter than it was?

Definitely. In all the charitable organisations that I support, in every single committee that I'm on, money is now the top talk. How do we get it? How do we provide something different so that we can get the money? And I mean the trouble is I'm not in a position really where I can give lots of money to anybody. I can give the odd fiver occasionally but I mean that's not what... a lot of money is needed. I mean Ability Northampton's looking for money. I can only give them little bits of money. And although that helps, it needs an awful lot of little bits of money to make anything positive.

And in terms of being able to turn to an organisation or an individual then for advice and support in continuing with Direct Payments and Independent Living as we're calling it, where are you able to turn?

Well I think the thing that I always find helpful is that at least most of the organisations now pay me transport money, which makes it more possible. And some even pay for my care.

This is in terms of the voluntary work that you do?

Yeah. And this is very good because it makes things more possible. I mean, I remember back in the days before I had the van and I remember using disabled taxes when I couldn't get into a car, and I spent well over £100 a week, just getting to meetings. You know, so I'm glad that there is a recognition that if they need your expertise, they're at least willing to give you petrol money, because that's what makes it viable, that's what makes it means to me, that I can go and do it. Whereas if anybody doesn't give me anything, it's got to be local.

And the profession of being a carer, that I suppose in terms of the variety of circumstances that people find themselves, that's a relatively, well, expanded profession I suppose. Where do you find your carers?

Advertise. It's been really hard cos I was without one carer for nearly a year, and I've got a 61 year old man now. I think the biggest problem is the amount of money that I can pay. If I could pay just that little bit more I would get a much more professional person, and I'm sure this is the view shared by other people on Direct Payments in Northamptonshire as well; I don't think it's a view just held by me. But I don't know how we solve that. I mean, yeah, I tell... he's quite concerned. But you see people that have money don't realise what it's like. They can't visualise what having 24 hour care is, they have no concept.

Well, how indeed can you make representations then? How can you make your views known?

Well, I meet them basically. I mean I sent a prepaid letter to this MP...

This is your local MP?

... He's not MP for Wellingborough; he's MP for another place in Northamptonshire. And he was immediately impressed because I put my arguments and I wasn't like a bull in a china shop, I was quite reasonable. I didn't suggest too much, I only suggested that, you know, people didn't realise that this amount of money is insufficient to [?] because I find that talking to people you get it across eventually, but

there are so many other claims for money that where your claim fits in I haven't got a clue.

So, in that way then do you feel that there isn't the awareness of just what it means to be and what the needs are?

There definitely isn't enough which is why I do it, and why at the moment I'm doing a campaign for people who are bed-ridden, who can't use a telephone, who might get burgled, so that they can get cameras or video equipment so that they can see who comes to the door before they let people in. Because in Wellingborough alone there's been a massive amount of people who have let people in and have lost things. And I mean, I have a friend with learning difficulties. Somebody got in the home where he is, cos he's in residential care, got in the skylight or something – I wasn't able to find out exact details cos he couldn't tell me, not because he didn't know but because he couldn't put it into sentence form – and stole a mobile phone or something. You know, and also, you see he goes to the police because that's what he's been taught to do, but because his communication skills are virtually nil, they don't understand him at the police station and he just doesn't get the right [?]. They sort of say to him well thank you very much, you know, whereas the home that he's in needs sort of need a safety sort of session. But you can only suggest things; you can't make things happen sometimes. I really wish at times you could, but you can't. You've got to bear in mind that people have their own opinions and they might not be your opinions and you can only do so much to influence people's opinions.

So we've seen the bringing about of a circumstance then where individuals like yourself are having to make individual representations, acting as an employer. What's really your comment on that circumstance?

Very hard because I didn't know anything about employment [laughs]. And I didn't know where to go to get it because I went to social services and they didn't know. I went to the solicitors; they didn't know. People just did not know. [Laughs.] It's like hunting for a needle in a stack! It took me five years to get a contract sorted out, simply because people just didn't know or weren't telling. And if they did know they

weren't telling that they knew, I mean which is why I try and share information, cos sharing information is so vital.

[Interviewer says something about tape.]

So, I mean, did you imagine then, you know, when you were younger, that you would be in the situation you're now in?

I don't think I could ever imagine. [Laughs.] You just learn as you go along. I really don't think you could imagine cos it's too difficult a concept to imagine. That's what puts people off – the fact that there is nothing concrete about what is going to happen.

So what are the solutions, would you say?

Better communication between agents and better communication between people. I mean more understanding of what people need. You know, I've been doing this for years and sometimes I feel just... Sometimes when you get into situations about money, you don't take any steps forward at all, you're still battling the same man or whatever, that you were battling years ago. Situations have changed, yeah, because years ago people didn't earn so much and years ago there were packets of money around. Now there's not the packets of money around and people don't seem to see caring as a profession. It's as professional as begin a teacher for goodness sake. It is for you to get the best out of it. I mean, you're only trying to live like any other person, and you need care to help you to do that. And I mean I get more care the way that I'm situated than I would in a home, you know, because in a home I'd have to share everything.

We'll just flip the tape...

[End of Track 20]

Tape 12 Side B [Track 21]

One of the things that delights me particularly is that places are getting more accessible. So it does mean that you can go to places with people, which is great.

And that's the, you know, changes in physical access to places. When did you first become aware then of there being now more and more places than that you could get to?

I've always been aware. Simply because, to me, access is the reason how you get out and about. If you can't have access to anything you don't go out and about, you know, simple as that. Again that is something that some people don't challenge, or don't always challenge it, because I like nothing more than being sociable, and being sociable means I have to go out to be sociable, because when I've gone out it gives me necessary rejuvenation to keep going. And that's how I manage to keep my calmness, if you like, in dealing with situations. Because I've seen so many people and done a fair few things and enjoyed myself and had ups and downs, and because you go out and about you learn different things and you learn that shouting and screaming isn't always the answer, at least it never has been in my case, but if you work away at things, you're gradually chipping away things like prejudices, injustices, and you're helping build a society which understands a little bit more about the problems of living here. And one of the problems of living in society is access, and it's something that I have been able to do something about because as an individual I can tell somebody that there's a problem in Wellingborough, and get something done about it. It is not so intense as the money problems which you can't do a lot locally about. It's got to be national; it's got to be almost international, if you see what I mean.

And in -

Whereas access, that's also national and international but it's more possible to solve the problems because the people, somehow the messages get back and they're done.

And in terms of the introduction of the Disability Discrimination Act and general attitudes of let's say restaurants and pubs and cinemas and so on, have you noticed an impact in particular in recent years?

Yes, I think so. I still think you get your black bits. I mean 20 years ago I was turned out of a pub for just being disabled because the regulars or the people, not the regulars, the people that were there just objected. I've not had that happen now, and indeed I deal with it, do you know what I mean? [Laughs.] I'm not being funny but years ago I hadn't got the expertise to deal with it. Now I've got the expertise to deal with it and can do something about it. Or at least sort of start a chain reaction if you like, to change things. And I think that is most important because there's still an awful lot of people who won't change anything and who don't see the need to. But they're not in wheelchairs; they don't have difficulty getting about.

This is people who provide a service in particular do you think?

Yeah, yeah.

So in terms of, you know, changes generally in perception and in attitudes, if you like public perception, let's cover that first of all; how do you think that may have changed recently?

I think a lot of work was done certainly 10, 20 years ago, about involving people with disabilities into schools, you know, to give talks and things. I'm awfully sorry to say that I think the video age has taken over and I'm not sure that's as good, because kids can watch a video, it's not like listening to me talk, saying what I like, what I dislike, who my favourite film star is, even something as banal as that, if you see what I mean. Lots of the kids that I gave talks to 10, 20 years ago, remember me still. I bet if I said to them, have you seen a disability video, they might not remember it. It's something to do with how you put it over and I'm sorry that the schools have sort of not used people like they used to. And I know 'use' is a funny word but I think it's absolutely vital that you get what disability is over to people when they're young, so that they can cope with it when they're older, and not get into this situation where I don't want

to know but which I think teenagers go through with anything. I don't think it's particularly worse with disabled to anything else.

And, if you like, as people progress through their lives they may have had opportunity to have contact with a disabled person, they may not have done, but people generally – how aware are they compared with past times?

Well certainly in some slices of society much more aware. I mean I do a Phab course at Westminster every year, I've done it for the last 25 years, and a vast percentage of Westminster's students who go to school there do Phab and end up being doctors. And I think we're a major influence. I mean they might be clever enough to be doctors but after they've done a week at Phab they know how to get somebody up and put them to bed, they know how to lift people. I mean, OK it's basic, but it carries on through their lives; they don't get in half the flaps that other people get in that have never done it.

So is it a matter not just of disability being higher on the social agenda but then being higher on the political agenda in turn?

It needs to be much higher on the political agenda with many more people involved than there are at the moment. I mean, there's very few people at the top with an... I mean, you hear the same names time and time again. You know, it's the same people carrying the flag and whilst that's OK they must feel overloaded. Cos I know this is why I go on holiday because even I get overloaded at times, you know, I think, 'Oh my God, what on earth am I doing this for?' It suddenly comes to me in the oddest sorts of ways. It's when people say thank you for something. You think well, if they can say thank you, you've done something for them. Therefore if you've done something for them it's not all black, it's various shades of colour to white. You know, you might be feeling desperate one day thinking I'll pack it all in, I'll chuck it all up, I don't want to go to any more meetings, and then something will happen and you'll wake up the next morning and you know darn well where your perspectives lie, you know, where you're going. It's just that like everybody else, things get a bit bad and you question why, which proves that you're human.

And if you could now, if there was a younger Dorcas sitting alongside us, perhaps Dorcas at 15, 16, 17, something like that; what would you say to your younger self?

I would like to encourage people in every sort of way. I would like to encourage it so that more people did things for disabled people so that there wasn't this awful void of lack of understanding, lack of common sense, lack of understanding. I'd like to get rid of prejudices, which is a hard one cos I know you can't cos prejudices come in all shapes and forms. But I'd like there to be a lot more ordinary people try because the new carer that I've got had never done caring before. He said afterwards at dinner once, he said, 'I wish I'd have done this years ago.' So you see he'd been in the print trade all his life, he knows everything that there is to know about printing: he's done hand printing, type printing, printing everything under the sun, but if he'd have known what caring was about, you know. And I suspect that there are people out there that if they knew, and caring isn't just about caring for people in residential homes, it's caring for people even if it's a next door neighbour popping in, you know. And until we get attitude changes about what things are, then we're not going to get anywhere, which is why you've got to start with the attitude changing bits. It's hard work, I don't think anybody ever thinks it's easy, cos it isn't. But it's going to happen because, I mean, you get organisations for equality, and I've been on to Wellingborough equalities thing – the group for the council that's part of the local plan, part of the local strategic plan for Wellingborough. A lot of emphasis is on the different ethnic groups because there's a lot of different ethnicity in Wellingborough, and I'm not just talking about black people, I'm talking about all different kinds of ethnic groups. But talk about the problems of equality for disabled and you are on a complete... they just don't know. I have sent the DRC [Disability Rights Committee] equality report to various people because that is the sort of thing that will move councils. It won't move the average person in the street who's got to wade through it cos it's not an easy document to wade through. I've waded through it but then I'm used to wading through documents.

The DRC – Disability Rights Committee, of course.

Do you know what I mean? But it goes down because it's statistical as well. And that is what changes councils. If you can produce the statistics, you can get something

done, but it is proving the statistics. I mean I'm not a statistician; I'm not a statistic person. To me, if there's a problem, you hear what that problem is and you do your best to solve it. And to me that doesn't include statistician information, but if they want statistician information I'll find it somewhere.

So there's a law, there's evidence in the form of statistics and other forms of detail, which can be presented to decisions makers. But really you're also saying that individuals then, by making representations through groups, you believe then can contribute to making a greater understanding?

Oh I'm sure. I'm sure, I've never given hope up, I'd never give up hope on society; if I did that that would be the end of me. I can't do that. I've seen too many good people. I've got too many good friends. And it's the good friends that keep me going because it's the good friends that know where I'm coming from. And, you know, I mean, I've had too many good experiences to throw everything overboard; I'd never contemplate committing suicide for that reason. I may feel desperate, I may feel positively awful at times, but I don't give up cos to me that's an easy [?] to give up. It's much harder to keep going, but having said that I'd rather keep going than give up.

So what, Dorcas, is your message then to decision makers?

I'd like to say come and visit, come and see. Or at least try and find out. Don't just ignore it; don't think that what you're doing is the complete answer because it isn't.

And so it's decision makers then, having a greater awareness of the lived experience of a disabled person?

Yeah. I still don't think people are. People are self-contained units and they behave self-contained. This is why what you're doing at Scope is so very important, because what you're doing is providing the evidence.

And if we, you know, compare the circumstance now, let's say to 25 years ago, perhaps there was in real terms more pots of money around you're saying potentially, but how do you think things have... does it feel different from let's say 25 years ago?

Twenty five years ago it was easy to get money. But 25 years ago access was not very good, and I would say more people are aware of disability now, but then more people are aware of lots of other things as well. And it depends where they particularly favour. I mean, Britain is a great country for supporting all sorts of organisations. People like their pets, and I have no argument with that. But I still think people need help, particularly people with multiple disability if you like, or people who find it difficult to communicate. They need help. I mean, my friend who's 50, who can't communicate: his parents know what he's on about but I don't know that anybody else really does. And what's going to happen to him? And it's all very well to say to the parents, 'What's going to happen?' They don't know either cos there isn't any... They'll all run round like chickens with their heads chopped off when anything happens, whereas I'm not saying it's parents' fault, I'm not saying it's anybody's fault, but surely a little bit of preparedness would help in situations like this. I mean the two parents are in their late seventies, early eighties, they worry about it, course they worry about it. But they can't find the options because either people don't want to admit that there's a problem there and that they can't do anything about it, or people just sit on it. It's going to happen someday. You know, and I find people get very apt to forget and not want to see what is happening because there's so many other things happening as well. And I think that is the biggest problem of modern society; it's running at such a rate of knots, far faster than 25 years ago, that it's easier to ignore things if they're not put in front of your nose, and if you don't support that thing you never will understand that thing.

And proof then that an individual can contribute, can try to make a difference, and above all, I guess, it's a life lived, which is important. The contribution that an individual can make, it is important I think – we were referring to this earlier on before we began recording – well, a life lived is a life lived really.

A life lived is much better if it is lived to some measure of how that person wants to live it, rather than the way the person doesn't want to live it, and a life lived is much

better if people around you are prepared to help you. If they're not prepared to help you you begin to wonder what life's about. You begin to lose faith in things. And I mean, I think there's a lot of poor tormented souls around and – OK that sounds a bit like a Victorian melodrama, but I'm quite sure it is something like a Victorian melodrama to those people. And you're not making it up when you say that people get depressed. People with disabilities are just as able to get depressed as anybody else, and it takes an awful lot of get up and go and common sense to sort of weather everything.

And when you look back on the involvements that you've had, the achievements that you've achieved, what are your thoughts about that?

I was very lucky with my parents. They gave me something; they gave me the get up and go, and for that reason I don't want to lose my get up and go because I think in some ways I'm repaying what they gave me. Because there wasn't the services around when I was younger, and because there wasn't the services around it must have been really hard for them. And I owe them a tremendous amount to keep going. I don't regret anything, I mean I do sometimes think, 'Oh I wish I had a man,' but I mean I don't get into a situation where it all [?] me and I get depressed about it because I've got my friends and that is a great comfort to mean we're still friends, whatever. And I think that in a way is very important, that you don't lose friendship.

And I suppose, you were saying that, you know, when you were first alive and your parents were bringing you up that there wasn't the support networks that there are now, and yet now we're in a circumstance where those support networks which do exist, there is a recognition of there either being these support network, but crucially there is the need for those services to be funded.

Yes. Much more so. I think, much more so. I think we had a great growth of, you know, organisations, which in the beginning was fine. But now there are so many organisations that there's almost no sharing. If people could learn to share the information then resources could be spread wider because people would know that so and so was doing something so we needn't so that; they can have the money for doing that; we'll do what we can. And people get very unhappy about sharing information

saying what they do because they think, 'Oh my funding's going to be cut,' and they don't want that so they don't share information, so they become little isolated bodies of information which is... to do a good job and not finding the answers because the answers aren't there.

And all the time I suppose are you finding that, you know, organisations are themselves then restricted in what they can do by funding and there are many and various organisations, some of which have limited funding, and so the circle goes round?

Yeah. And I also think you see that it is very restricting if you can't help somebody, because that person, it may be the only avenue they know. And people need signposting. A signposting service has got to be good. And, OK that might mean more junk through the letterbox, but how do you help people if they don't know there is help available?

So by signposting you mean that people get directed on to appropriate organisations and information according to their particular needs?

Yeah. And some people never get there because people do get embarrassed about their disabilities and a lot of work has to be done, A: to provide the support that people need, but B: to provide the [?] support.

So when you say people get embarrassed, they're what, becoming reticent then to say what their actual needs are?

I don't think it's so much about what's necessarily wrong with them, although they can be reticent about that; I think it's much more about, if it's finances: 'Where do I go?' You know, and I mean, we read it that so many people won't claim for this that and the other. I think a lot of it is because when you do claim you have these massive books to fill in of information, and it just puts people off because they think, 'Oh I'm not going to get what I want this way,' so they don't.

It's a matter then, is it, of seeing payments as being entitlements?

Yeah, yeah. And I think there's all sorts of problems round that area. There's all sorts of problems about if you do go and see a person their attitude to your disability makes such a difference. If it's a good attitude you'll carry on going to see that person and get something out of them, if it's a bad attitude you might not go again. You know, I mean I went. I've had problems. I've been to a housing department to get housing benefit, and one of the women we went to see was horrible. Where her social graces were goodness only knows. And I do find this. You get people who just don't seem to have any social graces whatsoever. Well if you're dealing with a person who's a bit unsure that can put them off completely. It didn't put me off, I just came out and said, 'Oh that wasn't very good,' and went. And eventually it was solved, and I went back again this year cos I had to go again because they queried me, because departments won't talk to each other, and I got a totally different person who was really very nice, and all we had to do was say a few words to her and she understood. And her social skills were much better.

And so where did you acquire, you know, this confidence, this determination from then?

[Laughs.] I don't know. I mean I wish I knew that but I think it's part of me. It might have been part of my dad because he was a businessman and he belonged to organisations. My mother was a very calm lady; she would give things to people. So I suppose I get my generosity and understanding of people's problems from her, and from my dad I get my, you know, committee procedure, that sort of thing. I don't know. I've thought about it a lot and, I mean, I think it's because there were people at Delarue that went to university and didn't get very far. They got through university but they certainly weren't placed anywhere. And I was determined that my life; I wasn't going to go to university [laughs], it didn't interest me, but people interest me. Because I became interested in people I also became knowledgeable about problems and how society's [?] and how it doesn't [?]. And I think this is where it all comes into play. Because you can't fulfil yourself in one role it doesn't mean to say that you're useless, you find something that you can do and it's a something that I can do rather than what I can't do.

[End of Track 21]

Tape 13 Side A [Track 22]

OK, Dorcas. Well we're in a situation nowadays then, with organisations and establishments existing – funding of course is another issue – but [coughs] excuse me, how is it do you think that people in previous years then, without that framework...

Well I know...

... began to manage?

I know my mum and dad certainly never had a lot of help. My dad was one of the founder members of the local Scope group, which is Northamptonshire Scope.

Or the Spastics Society, as it then was.

You know, local-wise, which got off the ground because at that time there were people with cerebral palsy surviving. And because the people with cerebral palsy were surviving it was decided to set up a group that could help those people and support those people. My dad used to go out and talk to people and advise people. He often said that they got too bogged down with the committee bit, the procedure bit, which I think can happen but then they're safeguarding the money that's been given to them, which has to be taken into account as well. But there again, so does people's needs, you know. I think without support you've got to be a very determined person to continue and to be able to rationalise what is good and what is bad. I didn't have a proper pram; I had a Victorian pram, which was like a bed. You know, you laid in it, it [you] didn't sit up in it, you just laid in it, and it had four wheels and it was made of wicker and it used to just go down our passage – cos we had a passage in our first house that I was born – and I was talking to a 90 year old the other week that remembers me from that time. And it's fascinating because I don't exactly remember myself as a baby. I remember myself when we watched the coronation and things like that, but I don't exactly remember myself as a baby. I do know that I cried a lot, and I do know that mother didn't know what I was crying for. So I really do applaud the people that helped in those days; not only helped but who gave mum support, and who seemed to have had faith in me, despite not knowing what was wrong with me

because I wasn't diagnosed until I was two and a half. And, you know, I mean I can't imagine what my parents went through. I know that they were determined to have me even though I was small. And this determination carried on, and I don't think my dad ever thought about me being minus, he always saw the plusses.

And in those early days and before the diagnosis and indeed after it, where did the support that your parents got, where did that come from?

Family basically. Great aunts surprisingly – great aunts were very good. But the nurse used to pop in (the normal thing that happens after birth) but they didn't know a lot. The doctor was a very old fashioned doctor and I perhaps owe my life a lot to him because he used to say '[?] and olive oil. Give her some brandy if she's poorly,' and, you know, all those sort of old-fashioned ideas, and I seem to have survived. Which, to me, gives me tremendous encouragement, tremendous encouragement. The more I think about it, the more I get encouraged by it; the fact that I did survive. The fact that I'm here for a reason, cos I could have so easily gone under. I'm sorry that my parents weren't allowed to adopt because I think that was the second biggest blow to my lifestyle, because I would have loved somebody to have been around who was my sort of age, who was... I mean it doesn't necessarily follow that we would have got on; I mean [there would be?] times when we would have hated one another. I don't mean hate because I think hate's too strong a word, but we would have disliked one another, and that sort of... And I suppose when they told me that, that was the biggest single thing that made me feel disabled, because I don't on the whole think with a disability label. I think with a label but it's not a disability label.

Just remind us if you would as to the reasons that were given as to why your parents weren't allowed to adopt.

Pardon?

Just remind us if you would of the reasons that were given why your parents weren't allowed to adopt.

Because I was disabled. Because I was disabled they said yes to my parents and then as soon as they knew that I was disabled they said no. And I was at school at the time, I was 12. And I think it was the biggest single thing that threw me. I was very, very upset about it, very upset. Not because I'd contemplated much about it, I mean parents had done this when I was away at boarding school, and I don't think they'd prepared me for it in case it didn't happen. But to be told that that was the reason they couldn't adopt, and they so badly wanted to, I felt awful that I had sort of somehow made things worse.

It was surely just the rules of the time, however one might regard them now. But in terms of, you know, involvement with and reaction from what we might now term 'support services', what kind of ongoing contact did you have with health services and social services as they would now be described?

Well, when I was at home before I went to school – I went to a day school to start with and health services provided the ambulance for me to go. I mean nowadays we'd have to get ourselves there. But I mean my parents never had a car. The only car my dad ever drove was in the air force cos he'd got a licence to drive, but he wouldn't take a test, he used to walk to work. You know, I mean you're talking about that sort of age of people where not everybody had cars and certainly it was a time of great excitement because it was when Scope was developed and it was when these organisations started coming together. So I suppose they were having learning processes as well. And like everything I reckon it takes years to get people's minds to accept organisations. I mean, yeah, I know about accepting disabled people. It takes people years sometimes to accept you in the community. You carry on doing things and you're hoping that they will. It's like people talking to you at church. When you first go to church people don't always talk to you and when you're disabled as well you've got the double problem – A: of people not wanting, not talking to you, but B: your disability which puts them off even more so some people end up never talking to you because they can't get over the hurdle. There's some frightened and some prejudiced people in some cases, that stops them doing that.

And in recent years of course we've seen in particular the increasing involvement of disabled people in organisations, but...

I wish there were more. I would dearly like challenge – I love challenges you see. I would dearly like to be able to employ somebody as a carer and do something professional that was really good, cos I think I've still got it in me. But since I'm coming up to retiring age it's a bit difficult because people are still not prepared to pay for the necessary help for you to do the things, even though you know that you can do things and so things well. I personally like to do things well, I think if you only do a half-baked job, then people can turn round and say, 'Ooh he's disabled, that's why it's like that.' And it shouldn't be that at all, you should be able to give yourself the very best. And if you give the very best and produce the very best then people can't turn round and blame it on to disability.

So is it a matter then of, you know, continuing to question, continuing to make your point?

All the time. I mean, some days I don't have meetings so I don't have to press, but if I can I will. I mean, that is partly what got me involved with this MP that I was going to visit but didn't happen because he had to...another meeting. But I mean I felt that I'd got somewhere, and the meeting has only been postponed, it's not been taken off the book so I might still go down and have a lunch with him, which I think will be really useful. I'm really sort of looking forward to that – A: because what I said obviously meant something to him, which is a great compliment really in a sense because you don't know when you send these things whether they are just going to be totally ignored, answered by somebody else or what.

And what would you say, Dorcas, if in the room here we would be sitting with the parents of a baby with cerebral palsy. What would you say to those parents?

Don't give up. Always try and think positive. There's something there. I have seen disabled people enjoy life, given the opportunity to try and do that. Don't say, 'Oh, don't wail, you know, people start wailing and questioning why – we don't know why. Ours is not to reason why, you know, and I really do think that it is to do and die. Because everybody dies in the end, but it is to do certainly. You know, I mean, I think that is the most apt thing, not to question why cos you start questioning why and

there is no answer, so why bother? You know, it doesn't solve anything, it just brings up my problems and my uncertainties, and really you don't want those sort of uncertainties, you want to be able to think well... I think one of the greatest things that I learnt – and I learnt this a long time ago now – one can't move mountains as an individual, perhaps as a body one can move a bit more, but as an individual it's much more difficult. But one can move grains of sand and even if you only move a bucketful in a lifetime at least you've done something for humankind and, for me, that's the reason for me being here. You know, everything has reasons. If you start going down the non-reason and the negative, you'll soon finish yourself off because you won't see the purpose of life. And life is wonderful. It can be a bugger at times – pardon me for swearing – but it can also be the most wonderful experience out. You know, like going to London two days ago. It was raining, we walked in the rain. Years ago people would have said, 'Oh you can't take her out in the rain – she'll catch cold,' you know, and it is so nice to go out in the rain and so nice to be able to go and visit places more and enjoy it, and be enthusiastic about being alive. It's so important because that way if you're enthusiastic about things you do, you'll get your message across because it's there. People think, 'Oh that was nice, she's happy.' You know, because there is still this odd perception that when you're disabled you're sad. I've had that thrown at me time and time again: 'Don't you ever despair?' 'Yes. But it don't make me sad, it's a passing phase. You crawl out of it.' You know, it's all about those sort of things that make life worth living.

And more opportunity now with improvements in things like access, to be able to go out into society and participate and see and be seen, which has to be an improvement.

Yeah. Oh definitely see and be seen. Definitely. I see no point in hiding away. What is there to hide? You're only a person. Because that's what I am. I'm not a disabled person; I am a person. And that is what is so important; the fact that I can't do certain things to some people is much more of a problem than it is to other people. It isn't really a problem to me. You know, I mean, I go on holiday, I enjoy myself, I do what I want to do, I'm reasonably live, reasonably successfully, even with limited money. But one thing that I would add to that is the plea that the government sees that sometimes the help they provide is not quite adequate enough. But they really need to see it from the bottom of the pile, not from somewhere like up above. And I know that

affects a lot of people because there are many more people than myself on benefits that need help and that sort of thing. It's just that they see it a little more clearly because people earn such phenomenal amounts. I know people give to charity but I still wish people realised that the people at the bottom don't get nearly as much. You know, that's not being sort of overbearing about it, that's just using a bit of common sense and practicalities about it. Because I do see the gap widening rather than narrowing and that's what worries me. If the gap wasn't widening I don't think I'd worry so much. But I feel that the gap is widening and in terms of employing people it's certainly getting a lot more difficult to employ people to care.

And in terms of the employment possibilities for disabled people, what are your observations there?

Well I suppose in a sense because I was told that I would never work, I put my energies into doing other things. And I suppose it's only been in the last 10 years that I've really questioned that because I've been quite content doing what I do. I mean, not content where I'd accept benefits if I could do anything, but I'd need a pretty good wage to cover my care bill and it's not worth working if you're on care.

And when was it, you know, given your involvements in voluntary groups and other organisations, when was it first that people in numbers if you like, started to come to you to ask you for your opinion of things and your expertise?

I think as soon as I started having community service volunteers. As soon as I started having help in. Certainly, I mean they did ask before, because I've gone out and found people, I've gone out and found organisations; I've gone out and done things for organisations. Some people always ask if you do things – you get asked. It's when you don't do things that you get negatives. So I suppose yeah, in some ways always, but certainly when I started organising my own care, even if it was only through CSV [Community Service Volunteers]. They asked me more because I was getting out more and, I mean, getting out was never a problem, I always got out but, you know, then you start meeting more and more people; that's when they start asking you to do more and more. And that is still the case. I mean, occasionally I have to say no. And occasionally I don't go to meetings. Sometimes because I'm double booked,

sometimes, once or twice, because I've just got up in the morning and felt completely anti-meeting. I should say that's only happened two or three times, but it does happen occasionally and you have to acknowledge it when it happens because there's nothing worse than being at a meeting or going to a meeting that you don't want to be at. It's counter-productive to the meeting and it's not good. You know, it's not good for the meeting, it's not good for you, it's not good for anybody else at that meeting because you're just not with it, you're just not interested. You know, and so you do have to rationalise things out.

And, of course, now we're in a situation where there is the opportunity for individuals to become involved in groups and other organisations, and that's not always something that people can do or are able to do. But what would you say then to others who are, if you like, teetering on the brink of becoming involved, of making their voice heard?

Do what you're interested in. Because if you do what you're interested in you become interested in so much more, because everything has a spin-off. I've never done an organisation yet where there's not been some sort of spin-off, where it's led to other things. I mean, one of the greatest things that I'm involved with is being a board member of the local theatre around the corner. I mean, it's a pleasure cos it's not about disability, it's about being a board member, and it's about contributing. OK part of what I know is disability, because I know that best. But it's not about that, it's about going to the theatre, it's about people's enjoyment, it's about good relationship with the staff at the theatre, it's about knowing where I'm coming from and where I'm going to, and it is so enjoyable.

And in all these sorts of circumstances of course, as your involvement with groups goes on, people come to know of you as Dorcas, and not just somebody with a disability but as an individual.

Yeah, and that's why you do it probably as well, that is another good reason for doing it because that's what you're trying to tell people – look I might have a wheelchair but my mind is not disabled, my mind's as free as a bird. I could go flying if I wanted to – I don't want to but, I mean, you know... Disability is a thing that you get, but it's also

a thing that other people chain you to. In other words some people make you much more disabled than what you are by attitude, by lack of understanding, so if you can work through that then there's a lot less negativeness if you can work through that one and show people that being disabled is not the end, it's only a new way of looking at things, then you're there, or at least you're getting there. I mean you're sort of able to do more. Because I can go round the Castle; I don't necessarily – my carers take me round there but I don't necessarily take a carer, they leave me and come back for me.

The Castle the local theatre.

You know, and I enjoy whatever I... If they want to go, I buy a ticket for them. If they desperately want to. But I go by myself and enjoy me own thing because that's what everybody else does. If you want to go and see a ballet you go and see a ballet. If you want to go and see grand opera you go and see grand opera. If you want to go and see somebody making a fool of themselves you go and see somebody making a fool of themselves. But everybody should be able to do these things and get enjoyment from what they do. There's no point if they don't. I mean, I enjoyed London. It was raining but it was enjoyable, it would have been nice if it hadn't have rained – even I admit to that – but it didn't stop me enjoying my [time?]. And, you see, so many people think that you shouldn't do things. And it depends on what influences people have in your life as to whether you end up doing them or not doing them. And so many people end up not doing them because they have been advised not to – I think that's better than saying any other way – but the advice seems to take over, they seem to think that they should never be able to do, which is so silly because it's like telling a child not to stick its finger in its ear or nose or whatever, you know, because they might hurt themselves. Eventually they see the sense and don't do it. You've got to see the sense and that's a normal sort of thing. But when you say to a child you can't go out in the rain because it's raining, if they were able-bodied they'd go out in the rain – what's the difference between being able-bodied and being disabled and going out in the rain? I don't understand that. If I want to go out into the rain I want to go out into the rain. And that is where fundamental things go wrong because they start providing restrictions and the restrictions sometimes never get lifted so that person never experiences going out in the rain so they don't know whether they like it or not. It's

like going on a train: some people never go on a train so they don't know whether they like going on a train. And I've engineered one or two Jim'll Fix It things

for people. Very difficult because I know that I need help and the person that I'm engineering them for needs help, so you need about four helpers in order to do it. So I don't do it very often, but I have done it just to make sure that people have an experience. Because lots of disabled people go without having experiences and that's what stunts their ability to do things as well. You know, you're talking about fundamental things, things that are easy to do as well. Everybody should have opportunities to try things, unless they're going to do themselves physical harm. I mean, everybody should be able to go on a train and ride somewhere if they want to. Everybody should be able to go out in the rain if they want to. You know, I mean, they're easy things. There are things that are a lot harder than that, but that shows you the kind of restrictions that are placed on disabled people that, in the past, have hindered people's growth.

[End of Track 22]

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