



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

Pat Entwistle
Interviewed by Richard Smith

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Interview Summary Sheet

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Collection title:	Speaking for Ourselves: An Oral History of People With Cerebral Palsy		
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Interviewee's forename:	Pat	Sex:	Male
Occupation:		Date and place of birth:	1940, Colne, Lancashire
Date(s, of recording:	4 th April 2005, 25 th May 2005, 9 th August 2005		
Location of interview:			
Name of interviewer:	Richard Smith		
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Interviewer's comments:	A facilitator is present (Leona Bennett-Gibson), to aid the interviewer, and her words will be transcribed, except where she and the interviewer diverge.		

Tape 1 Side A [Track 1]

[A facilitator is present, to aid the interviewer, and her words will be transcribed, except where she and the interviewer diverge.]

Right, it's the 4th April, and I've come to Manchester to interview Pat Entwistle. Hi, Pat. Are you ready to be interviewed?

Yes.

Thank you. I want to start with your early years; so is that OK?

Yes.

I'd like to begin asking you when and where you were born?

I was born in a Lancashire town called Colne, near Burnley, on [aircraft noise] the 6th October, 1940.

What are your first names and why were they chosen?

I were christened Patrick Michael but unfortunately, at the age of two, I was taken into care, and so I really did not know me family. Apparently, I was one of 14 children.

Fourteen? Wow!

I was unlucky for some: number 13. [The other two laugh.] They didn't realise I was born with cerebral palsy, and at the age, my mother, I believe, suffered from diabetes:

Yes.

insulin twice a day...

Yes.

... in and out of comas, and on the day she was havin' me she was in a coma, and this is why I was born

Facilitator [talking together]: Right!

with cerebral palsy, with complications.

Interviewer and facilitator: Mm hmm.

And when I was two, I was taken into the Royal Burnley Hospital...

Interviewer [talking with facilitator]: Yes.

Facilitator: Mm hmm.

... with a chest infection, payin' on the 'Free List'. And at that point the paediatrician of the day got hold of me father and eldest sister, and said, 'This child, when he comes home, he will have to 'ave a room of his own. He's a very sick child'.

Yes.

And me father said, 'That's impossible, because we've got 14 children in a three bedroomed house,' so the paediatrician said, 'Well I've no alternative than to recommend that he goes into care,' and they never saw me again.

Facilitator: Blimey!

So really, as far as me [birth] family's concerned, I don't know a lot, because it wasn't until I wrote me autobiography, five years ago, that I really, properly, was able to contact me own family.

Facilitator: Right!

Mm hmm.

Facilitator: Right, that's...

Can I just ask you; why didn't your mum and dad keep in contact?

I haven't a clue.

Both: Mm.

Not a clue.

Facilitator: Right.

I was taken into a Convent at Patricroft, near Eccles, [St Joseph's Home], where there was 250 children.

Facilitator: Blimey.

It was a Convent, and I was the only handicapped child there.

Both: Mm.

Facilitator: Right.

So you don't know where your mum and dad worked, or anything?

Yeah. According to me birth certificate, me father were called Richard John,

Yes.

and he was what they called an 'artificial silk creeper'. [Voice in background.] Nylon.

Right, yes.

This was when nylon first came.

Facilitator: Yes.

Mm.

And don't ask me what an artificial silk [interviewer laughs] creeper is – I 'aven't a clue.

[Inaudible.]

And me mother, I presume, was just a housewife.

Both: Yes.

Right,

Mind you, she 'ad a job with 14 children.

Oh yes.

Facilitator: Well yes, a full-time job.

Can I go on to your birth?

Yes.

What do you know about your birth?

As far as I can gather, and this was what me sister told me, I was a breached baby with complications.

Facilitator [talking together]: Mm.

Yes.

And that's as far as I know.

[Talking together] Mm.

Facilitator: Yes.

What medical advice were your parents given: if you know? Right. What language was used to describe your disability, at the time? Or don't you know? [Two phones start ringing. Break in recording.] Language: what language was used to describe your disability at the time, if you know?

I haven't a clue. As I said, the only thing that I remember is when the paediatrician

Facilitator: Yes.

told me father and eldest sister, about takin' me into care.

Both: Yes.

What memories do you have of seein' doctors?

My first memory is when I was taken into Rochdale Hospital, to 'ave the usual tendons done be'ind the ankle bone.

Yeah.

In those days, you used to be in plaster about two or three years. They would put one on, take it off after a period, and [sound of crockery clanking] put another one on.

Yes.

And I do remember one day, I was in what they called a 'children's home', while I was waitin' to go into hospital [Home for Crippled Children, near Rochdale].

Yes.

And this paediatrician came – I'd be about five – and he said, 'Oh, Patrick. Would you like to play football?' so, I says, 'Oh, yes please'. So he says, 'Well, we've done everything medically possible. What kind of life you will have eventually is entirely up to you',

Facilitator [Talking together]: Right.

Mm.

and I've always remembered those words.

Mm. That were nice.

How did cerebral palsy affect you when you were young?

Particularly at the Convent, I got the usual, with me bein' the only handicap child there, . I got a bit rough, teasin', and I wasn't able to go to school with the others,

children. And the school was about two or three miles away from the Convent, and in those days I could hardly walk. I'd stagger, and fall down.

Both: Mm hmm.

That was my memory,

Both: Mm.

of the Convent. I mean I was treated very well with the nuns, but we must remember we're talkin' about the 1940s,

Facilitator [talking together]: Right, yes.

Mm, mm.

when disability... they had not a clue.

Facilitator: Yes.

Not a clue.

Facilitator: Definitely.

When did you first realise yourself, that you had cerebral palsy?

I knew I was handicapped, but I hadn't any idea what it was called. I mean I didn't even know about birthdays cos I never got any birthday cards or presents,

Facilitator: Right.

even at Christmas.

And how did that make you feel?

I just accepted it, because I didn't know,

Both: Yes.

you know? It was that way. What you didn't know, it didn't

Facilitator: Didn't harm yer, no.

harm yer. [Voices in background.] It was only later on, when I did find out, that it started to affect.

Facilitator: Yes.

What was the reaction of non-family members, like neighbours or friends?

[Talking together] I 'aven't a clue.

Family friends, or...? No?

I 'aven't a clue,

Facilitator: No?

because I was generally at home,

Facilitator: Mm hmm.

and we very rarely

Facilitator: Right.

went out, particularly meself.

Right, now I'd like to go on to early memory of [inaudible: facilitator talking same time as interviewer]. Right. What are some of your strongest, or most vivid early memories? Anything at all, can you remember? [Traffic noise in background.]

I think one of the main memories is, as I said, at the Convent when I was unable to go to school with other children. I used to be from, say, half past eight in the mornin' till about half past four in the afternoon, on me own, with just one of the sisters, the nuns. And naturally, with 'er bein' a nun, she had to go to chapel two or three times a day, and I would be left in a play room listening to the radio.

Both: Mm hmm.

They used to be long days, and I would enjoy more the weekends when the children weren't at high school – although they used to take the mickey out of me, running up to me, when I were tryin' to learn how to walk, pushin' me over, callin' me names:

Both: Oh yes.

but this is children.

Both: Mm.

Facilitator: Definitely.

I can remember havin' to be helped [traffic noise in background] upstairs to the dormitories, cos you must remember there was no such thing as lifts or aids, and I remember one day I had two lads helpin' me to come down from the dormitory, about

lunch time, when we 'ad to go down to wash our hands. And one day, this lad or two lads, had a great idea of layin' me at the top of the stairs and literally rollin' me down.

Facilitator: Oh dear.

And they just said, 'That's a quicker way to get down.' [All laugh.]

Facilitator: Blimey.

Of course I got bruised,

[Laughs]

Facilitator: I bet you did as well.

and in the evening, the sister who was lookin' after us, wanted to know where I'd got the bruises from, and I couldn't tell 'er the truth. I just said, 'Oh I fell and...'

Both: Yes.

otherwise I would 'ave got clobbered.

Facilitator: Yes. Oh dear.

What were some of the rooms like, including furniture, in the place where you lived?

Very good, actually. It, from the outside, looked like a factory. And the front door, naturally with it bein' a Convent, they had a large square grid with a wire mesh, what they used to slide this thing, and you could speak. I remember going there and bein' carried in by a social worker, but once you got in the buildin' itself by the entrance hall, it was absolutely beautiful. Very highly-polished floors,

Facilitator: Yes.

which wasn't ideal for me, or any handicapped person, because it was all polished and it used to be slippy. But again, it was something you accepted.

Facilitator: Yes.

What are your memories of meal times, and what were your favourite foods?

Favourites?

Facilitator: Favourite foods, and meal times; what were they like?

Again, you must remember that this was durin' the Second World War,

Both: Yes.

when food was rationed. Although we got a lot with it bein' a children's home. We got a lot more than what families on the outside got.

Yeah.

I can't really say. We was well-fed. We used to 'ave breakfast about half past seven in the mornin', cos the children naturally would be goin' to school about half past eight, to get there for nine o'clock.

Both: Yes.

And they did try to send me to school for about six months. And I remember the two lads again would be holdin' me up, and in those days we would probably meet people, or children, from the Church of England schools, and all the nicknames you could mention would be comin' out, and I remember [aircraft noise] them helpin' me to go,

and they started to fight [interviewer laughs] 'Proddy dodge' [fights between Catholic and Protestant boys]. [Inaudible.] And they forgot me, just let me literally drop on the pavement.

Facilitator: [Laughing] Oh dear. That's mean i'n't it?

Well, it's...

Facilitator: Then again, it's children, like you say.

... it's kids.

Both: Mm.

But it didn't work out, because I believe the school wouldn't take the responsibility.

Facilitator: Right, yes.

Cos even in play time, I wouldn't be allowed to go out with the others. I would just be dumped in the class room and not with them.

Both: Mm.

So it didn't work.

Facilitator: No.

What was a favourite toy, or something you played with?

It was a big wooden train, on which you could sit on... it was like a plank. And I would go on this more durin' the day, when the other children who were at school.

Facilitator: Yes.

Other than that, it was just... they were never your own: you 'ad to share. And same at Christmas – anything that were brought, it were for everybody, not just for you.

Facilitator: Yes.

The only thing that they couldn't share was shoes, cos I 'ad to 'ave black boots, so...
[Laughs.]

Yes.

Facilitator: So you got your own of that then.

That was the only thing

Both: Yes.

that was mine.

Facilitator: Yes.

What was a favourite book? And was what your favourite stories?

I couldn't read because I'd never been properly to school, so really I couldn't read, I couldn't write, and what I did write nobody could understand – it were more like Chinese.

Facilitator [laughing] Right. [All laugh.]

But you see, that's the difference – your education wasn't important. They were more concerned about gettin' you up and walkin', and learnin' the basic rudiments of life

like dressin' yourself, washin' yourself, bein' taught that. We're talkin' about the Victorian attitude, you know. Anybody with a physical handicap... you should be pushed in a corner, not seen. It was very...

OK then, thanks Pat. Now we're going to your early school days. Where did you first go to school, and what was the school's name?

Right, we're getting...

Or what kind of school was it?

... into this. This was a school opened by the Lancashire County Council, and we're talkin' about 1946. It was a school called Bleasdale House in Silverdale, just outside Morecombe, [Bleasdale House, Silverdale, Carnforth, Lancashire] and this was the first school ever in the country to deal with multi-handicapped children.

Facilitator: Right.

They nearly 'ad every sort of handicap. There was spina bifida, cerebral palsy, well, spastic anyway, , haemophiliacs, people with holes in hearts, and there was 25 children there when I went, in 1946.

Yes.

Facilitator: Right.

We had physical exercises,

Yes.

we had speech therapy,

Facilitator: Mm hmm.

and I remember we had a blue carpet laid down the play room, and we was taught to walk on the 'magic blue carpet' [interviewer laughs]. And also, what we had was, learn how to lace your boots up, because you must remember zips weren't out in those days, they were buttons everywhere [interviewer laughs]. So we 'ad a wooden frame, with two pieces of cloth on one side, the buttons on the other side, button holes, so we were taught coordination: how to fasten buttons.

Yes.

And then we had another frame with a woman's corset, so that we [interviewer laughs] learnt how to lace

Facilitator: Yes

our shoes up.

Facilitator: Right.

Very... but it worked.

Both: Yes.

Facilitator [Talking together]: It was a...

They were basic,

Facilitator: ... good way.

but a good way of learnin'.

Facilitator: Yes.

And the school days would be interrupted with either physio or speech therapy, and I had more for speech. And also, sun ray, well, about twice a week sun ray, , and this was to get, I think, it were the proteins or, thing, and then we'd be visited by either social workers, doctors, who would come along and pat you on the head. It's a wonder I haven't got a flat head.

[Interviewer laughs.]

Both: Mm.

How, you know, marvellous, you know? And then in 1952, as it proved to be a success, they opened another school,

Yes.

from 11 to 16, and this was at Singleton Hall, just outside Blackpool [Singleton Hall Special School], and I went there on 6th November 1951. And this was a much better 'open school' – it was in 25-acre land and it was there we were gettin' prepared for the big wide world outside.

Both: Mm.

But this is when I began to realise properly that I 'ad nobody, because visitin' time used to be once a month, the first Saturday, [banging noise] while the other children, lads, were havin' their parents, I 'ad nobody: nobody came to see me. I was purely reliant on the Lancashire County: when they went away for summer holidays, Christmas, I would either stay at the school or be sent to a reception centre for children, and this really did have an effect. In fact, it affected me that much that I began to start stealin' off other children, so not only did it affect me physically, but it affected me memory, like. Why? I think I just started askin' the question 'Why?'

Both: Mm.

Why 'aven't I got anybody? And of course nobody knew, because when I was taken into the Convent, the only question they asked was, 'Have you been christened?'

Both: Mm.

So of course there were no back history about it – they weren't interested in that.

Facilitator: Mm. Right.

Very interesting. Describe your first day at school,

At both schools?

and what was your age?

Well, I'd be about six when I went to Bleasdale House, and again I was carried in – not that I couldn't walk a bit, but it was more, you know, for safety reasons. I arrived late afternoon...

[End of Track 1]

Tape 1 Side B [Track 2]

Right I'm going to continue with [question] number six. What strong memories do you have of your early school years?

The school when it was purchased by the Lancashire county, there was no central heatin'. What they had was the old fireplaces and eventually they had to, think, put central heatin' in, which meant that they had to pull all the wooden floorboards up, room by room, and this took about three or four

[Talking together] Yes.

Facilitator: Mm hmm.

years to do. And we was all on one level, because there was no way that, [traffic noise in background] with the children that there were there, they could manage to climb stairs, and I remember us having to move from room to room while they pulled the floor boards, put the hot water pipes under the floor boards. And then, about two years into this, they decided that there was that many pupils needed to come, they would 'ave to put a lift into the building, and this lift was placed in the front hall plus in our playroom-cum-dormitory, and we was literally in the buildin' when they blasted the foundations of the lift, and all there was between us and the lift shaft,

Facilitator: Oh right.

was a sheet: nothin' else.

Facilitator: Oh blimey.

And we were there when it were blasted out, and this was to enable to go upstairs. It was a bit of a pain but it had to be done.

Both: Mm.

And we had very good teachers and very good carers. During the... we used to 'ave to 'ave a lie-down after lunch for an hour and we used to go on camp beds,

Yes, yes.

and when it were fine in the summer, we would be put out on the terrace. And I remember one day, a photographer comin', takin' the outside of the school from the Veranda and when the photograph came out, guess who was sat up on their cot bed? Me! [Facilitator laughs.] And it didn't go down very well, because you were supposed to go to sleep: there's no way. The education, as I said, were very limited, because they were more concerned about gettin' you walking and things like that, although they weren't soft with us. If we had said, 'Oh we want help'. 'Oh, help such-a-body,' or, 'Can you do a few more steps?' and you would say, 'We can't, no way.' 'There is no such word as "can't". You do it.'

Both: Yes.

And this was the attitude, you know? They wanted you to get as far on as you possibly could, and then in the long run it's paid off.

Facilitator: It's positive.

Positive. There was no negative –

Facilitator: Right.

they didn't like that. And of course, weekends was alright because we used to be playin' in this one room – we ate, slept and played – and considerin' these rooms, and eventually the whole school, was fitted with central heatin', and people used to think we was angels: they didn't know what we got up to. [Other two laugh.] I'm not gonna

[say] I'm that bad, we did get up to [things]: particularly the ones that was more mobile.

Yes.

And we 'ad very good staff, both teaching and carers, and they believed in us.

Facilitator: [Traffic noise in background.] Yes, that's good.

That was what... and they was dedicated. There was no such thing as watchin' the clock.

Both: Mm.

They didn't go off until the other staff came on.

Yes, yes.

Facilitator: That's very good.

[Interviewer starts to say something.]

There was no hint of abuse. A lot of people ask me if there was any abuse, and I can honestly say 'No way. There was no abuse at all. Whatsoever.'

Facilitator: That's very good.

What teachers were important? What memories do you have of friends at the school?

[Laughs] I have quite a few... [Laughs] in between fights. Well I had a few, but it was difficult because, as you can imagine, there was all types of disabilities, and sometimes we would try to do more than what we were really capable of doing. I

remember one lad who was spina bifida hydrocephalus, and in those days they couldn't get rid of the fluid from the brain, so this lad: all he could do was lie in the cot while his head swole and swole until eventually the fluid drowned his brain,

Oh dear.

and it's something that you will never forget.

Oh, wow.

Facilitator: Mm. I can imagine.

Well today they can put some 'shunts' in their... [attached to the head]. But these are things you got used to cos you had to, and you sort of helped one another. But it was a different case for me because the school was more than a school, it was my home, because I had nowhere to go. And in 1951 they opened a second school, Singleton Hall, near Blackpool, and this was for the pupils from 11 to 16, [voices in background] where they would be gettin' ready for you to go out into the wide world. Most of us went on special training colleges.

Facilitator: Right.

I went to Queen Elizabeth Training College in Leatherhead, Surrey, [Queen Elizabeth's Training College for the Disabled] and I chose gardening. I was there two years, but to me that was the biggest wrench in my life, because one day you would be treated as a child and the next day you was expected to act like an adult – and to me it wasn't easy.

Both: Mm.

And again it was harder for me because they were sort of taking me away from what I had called my home:

Yeah. Yes.

and there was no back up.

No.

If I felt low, there was nobody there that I could turn to, like others would have their parents or they could phone their parents: I just didn't 'ave...

Facilitator: Yes.

I was taken by a social worker to the college, and that was it.

Get on with it.

Get on with it.

I bet that warn't nice, yes.

No, but it was something I had to accept.

Both: Yes.

If I wanted to live in the community, then I had to go through this process with no backing. I was there for two years, but I was still under the care of Lancashire County. And then in 1958 I left college, and Lancashire County put me in a home for children outside Preston called 'Bamber Bridge' while they tried and sort where they're goin' to send me, and I finished up in a 'Home for Incurables' just outside Darlington. Talk about 'out of sight, out of mind', although I got foster parents here, cos I met a boy [David Robinson] with very bad cerebral palsy, and his parents [Margaret and Jack] took an interest. So this is how I came to Denton to live: well not live, but for

holidays. And so eventually, when I was 18, I came out of care and I decided to come back 'ere to live with his family, and that would be [horn hooting in distance] 1960. No job, nothing, and this would be the first time that I really got in contact [with] The Spastics Society. It was a Mrs Muncaster who was a welfare officer, and she found me a job at Dunlops in Manchester, and that's the first time that I ever came into contact with Scope, or the Society.

Facilitator: Yes

Right.

[Break in recording.]

Yes, I was in a children's reception centre at Bamber Bridge, just outside Preston, and at this time I had to sign-on at the local Employment Exchange, and the DRO [who] was the Disabled Resettlement Officer, found me a job at a nursery-cum-hotel [traffic noise in background, and rustling noise] just outside Preston, and this was a market garden plus a hotel, and it was there. I used to work from 'alf half past seven in the mornin' till about, could be, half past nine at night, from workin' all day cuttin' flowers, weedin' flower beds, boiling beetroot ready for the market, because the owner of the market garden used to go on Bury Market three times a week, and I would be left just cuttin' flowers and just labourin'.

Yes.

And the County found me a place to stay, and I was receivin' – you will not believe this – two pound a week,

Wow.

plus this board and lodge [board and lodging].

Facilitator: Right.

And eventually it got to me, because I would just [get] tired. It was the seven days a week, and I were goin' down the nick [police station?] so I was still in contact with [aircraft noise] the matron at the school, and she rang the Lancashire County up and said, 'This is not workin'. It's no good.'

Yes.

So, eventually I was sent back to this children's reception centre. Then they sent me to this 'Home for Incurables' in Darlington just outside Croft, run by the Brothers of St John of God [a nursing order of the Catholic Church], and that weren't for me because I just deteriorated. There was nothing to live for. And eventually I came back again to live in Denton, where I were found a job at Oldham Batteries, firstly as a messenger boy, cos I was only 19, . And it was costin' me about... I was havin' to buy shoes every other week, with walkin' all day, and it got too much. So eventually I was put in the welfare, where they dealt with like the overalls and I used to 'ave to sweep up, mop floors, the bath, toilets, and I was known as the 'Chief Petty Officer'.

[Banging noise. Interviewer laughs. Break in recording.]

And this went all right but, eventually, when I first went in, I 'ad a good foreman and he died, so they hired a chappy who was on the security and really he wasn't fit for this particular department. His attitude was that disabled people like me should not be takin' jobs up what able-bodied could do. But the point was nobody able-bodied wanted the job anyway [rustling sound]. So his attitude got me boilin' one day, and I just took a swing at him, and that was it: [laughing] out. It was a stupid thing to do, because I'd just been married, and we'd just had a daughter, so the last thing we needed was me to be out of work. Because we'd been fired, I 'ad to wait six weeks for the dole,

Facilitator: Right, yeah, mm.

so really [banging noise and rustling] it was a stupid thing to do, but at the time it was the only way that I could... And then eventually Mrs Muncaster from the Spastics Society contacted me and she found me the job at Dunlops Rubber Works in town – Cambridge Street [Manchester]. And I was there five years but I collapsed, and that, virtually, was the end of my employment because there was no other jobs they could find me. And so that is when my voluntary work started.

Do you want to move on to work, that work that you did?

At Dunlops? The work was, again, sweepin' and moppin',

[Starts to say something.]

but it was heavy, industrial cleaning.

Yes. Do you want to go on to your voluntary work that you did, or what you've been doin' with Scope?

Right.

OK.

Well, I'm goin' to lead up to that because some things are different. In 1974, I was approached by what was RADAR, which was the Royal Association of Disability, I think, [Royal Association for Disability and Rehabilitation] and this was to go on to a Transport User's Consultative [traffic noise in background] Committee [TUCC] for the north west of England, and this is for British Rail. And the area we covered was from Crewe to Carlisle, and it was my remit to deal with... it was a committee that dealt with complaints of the travellin' public on British Rail, and my remit was to make sure that there was access not only onto the station, but onto the trains. Cos in those days, there was very little on the rails and the first train that they brought out

was the Mark Three, which they was able to take the seat out, but this meant that any disabled person who was in a wheelchair had to notify them the day before, and it didn't go down well with a lot of disabled people. But what they didn't realise was that that carriage would have to go into the shed, the seat would have to be removed, then brought out, [traffic noise] and put on to the other part of the train. And I was on this committee for 25 years – it wasn't a paid job,

A long time.

you just got your thing [expenses; it being a voluntary position] and it was through that committee

Yes.

that I was, 1986, awarded the MBE. That's a photograph with the medal [in the room].

Facilitator: That's great.

Yes.

And it was then that Nigel Smith: I don't know whether you've heard of him?

No.

[Break in recording.]

OK.

Nigel was then the northwest Regional Manager [of the Spastics Society] and he knew about this position on the railways, and there was a big conference bein' held at County Hall in Manchester regarding access onto public transport, and he asked me

would I go along and speak about the work on the railway thing, and the same day one of the other speakers was Blunkett. [David Blunkett, later an MP and Government Minister.] He wasn't even a councillor then, he was speakin' about the position of people with visual impairment on the... [inaudible]. And in those days they'd had... somebody there had brought out a speakin' bus stop, and this was based in Bournemouth, and what it used to do was, it used to tell the person at that bus stop where they was, and the number of stops they would be stoppin' at, [sound of horn in background] but unfortunately they couldn't get anyone to take it up, commercially. It was a very big conference, very interestin'. And then the next thing that I knew was about the 'Kneeler' buses and the 'Readybus', so I was invited, with Nigel, to go to London to the launch of the Readybus, and Robert Dougall who was a, I don't know whether you remember, he used to be one of the interviewers on BBC One, he was there and Ken Livingstone,

Oh yeah.

'Red Ken', [interviewer laughs] and he launched this 'Readybus'. And then eventually they came on-stream, because we, as The Society [The Spastics Society] we'd already commissioned, or written and published, a book called Can I Get There? I don't know if you've ever...?

No, I haven't seen it.

No, right, well this is the first, probably, of any, and it was because parents of children with cerebral palsy were sayin', 'Look, it's all right talkin' about education, it's all right talkin' about leisure, but we've got a problem with bein' able to use public transport,' – whether it were bus, train or anything – so we did this report and it showed up a very big gap and I feel that was invaluable.

[Talking together] Yes.

Facilitator: Mm.

Since that book was published everything's moved forward, and everything was goin' all right until the deregulation of buses, and this sort of thing. And then I worked for Scope. [They] asked me, would I be interested... they launched something called *The Land of Droog* [a Spastics Society video designed to increase disability awareness]

Right.

which we 'ad to take round to infant schools, and it was animated, and basically what it was, there was three or four children: one coloured and two white, and one in a wheelchair.

Oh right.

And what we had to do was go to the school, show this video, and then we would ask the pupils, was there any questions? I remember goin' one day

Yes.

Erm, that's good.

to a school, and I covered 60 schools in Preston,

Facilitator: Yes?

in about six weeks.

Yes.

Nigel took me and Peter Clarke [from the Spastics Society]...

[End of Track 1]

Tape 2 Side A [Track 3]

Facilitator: Right.

Right. As I say, once we'd shown the video we took a pack with us, which the school children could do, and then we would go on to any questions, and it varied; sometimes the children were virtually waitin' for one pupil to start askin' but once you got them started it was very interestin', and there were two main questions that was asked.

Firstly, was 'Does it hurt?' and, 'Can you pass it on?' and of course, you know, I said 'No, the only hurt that you got, would be when the doctor was sort of testin' you, and

Yeah.

they hit, you know.' And I said, 'No you can't catch it, [interviewer laughs] you're born with it or it's passed on through rubella,' and I was very adamant on making sure that girls, particularly, had their rubella injections.

Facilitator: Mm hmm.

Yes.

And it was awkward sometimes, because I was goin' in to all denominational schools and it were difficult with the Catholic schools,

[Laughs] Mm.

Facilitator: Mm.

particularly about the contraceptives and all those sort of things, and I remember one day tryin' to make a point with the pupils about, I said, 'Do you know I can see a disability in this room. Can anybody tell me what?'

Yeah.

You know, and they couldn't so I said, 'Well, I can see a few pupils [voices in background] wearin' glasses'.

Facilitator: Mm. [To Richard:] It's what you say.

Yes, but what...

And I said too, 'How many of you here have called somebody wearin' glasses 'Specky four-eyes'?' Of course this kid gets up full in tears, and moves out you see.

Facilitator: Mm hmm.

I thought, 'Oh my God! [interviewer about to say something at same time] I've done something!', so the teacher said, 'Don't worry: he's always like that.' I said, 'Well I'm sorry, but I was just tryin' to make a point that, you know, well everyone's like that,' So eventually, typical Scope just chopped it, said there was no more money, and it was something that we felt, other people that were doin' it, that it needed to be taken [traffic noise in background] further, and goin' on to secondary schools.

How long ago was that?

I would put it in the eighties.

Is there any way you could take it to a [Scope] Partnership Committee?

[Interviewer talking at same time: inaudible.] Hang on. There actually weren't even any early Partnership Committees then. We didn't even have Alpha. Alpha

Yes.

weren't even set up. [Alpha was an initiative of the Spastics Society, consulting members of the Society for their views.] This is what I was going on to say: eventually, Alpha

Yes.

was set up and this I felt was a good thing because it was allowin' people with cerebral palsy, who was living with either relatives or carers, some of them couldn't even read, or they were bein' told what time to get up, what time to go to bed, where to go on holiday, and they was in their thirties and forties!

[Talking together] Yes.

Facilitator: Mm.

And I just said 'Hang on! You're in your thirties and forties, [interviewer laughs] you don't need somebody to tell you when to get up, where to go on holiday. You've got a brain – use it!' And of course, the big guns in London, we got too powerful, you know, they didn't like the idea of somebody with cerebral palsy tellin' them what, and eventually they decided, you know, Alpha wasn't workin'; we'll go on to Partnerships [Scope Partnership Committees]. Of course, I didn't agree with it [ceasing Alpha]. I thought, 'Well, we've got this far,' and we 'ad people comin' to us, even the carers said, 'Look, you've made a difference: they're speakin' more for themselves.'

[Facilitator misunderstands] Are you a member of Scope at the moment?

No.

Are you involved with Scope at the moment?

Mm?

Are you involved with Scope at the moment?

I am, well, I'm a life member.

[Talking at same time] Oh yes.

I was made a life member for me [voluntary] work, [interviewer saying something at same time] but I've not yet had the chance to receive all the... thing.

Do you go to the national forum?

No, I did do,

Yes.

as Chairman of Alpha,

Facilitator: [Talking together] Mm.

Yes.

and, you see, what I found was, [travel noise in background] we would send documents down to London, and we would find these, what we'd already spoken about, [in Alpha] put in their documents, and not even said... they would be gettin' the credit, and yet it was us, and we just got browned off with this, and

[Starts to say something]

I don't think... Alpha nationally, there was too big there, it depended on the area you lived; there were some very weak Alpha groups. Fortunately we 'ad one of the strongest, because we would go on and we'd say what we thought.

Was that in this area?

Yes. We were the Greater Manchester [Alpha]. You see, again, they'd change the boundaries. It was just Lancashire and Greater Manchester and then, in their wisdom, they widened it all to the north of England. Now you only 'ave one officer for the whole of the north of England, and it was impossible: they couldn't cover the area, you know. So you were very much dependent on the local groups,

[Both talking together] Yes.

and some of the groups were very weak. And what happened was, about three years ago, I went in the AGM [Annual General Meeting] in London, and I was asked would I pass the trustees' report on the thing, and what do I do? I collapse on the floor, and I'm taken into hospital in London,

Oh right.

Overnight.

Facilitator: Right.

And that's when they found that me blood was wrong,

Oh dear.

and I've not been fit since, and then I blame a lot of it on the work I was doin' for Scope. I mean, it was that ridiculous that me own wife had to book an appointment to go Christmas shoppin' [with me]. It was that mad. [Voices in background.] And

[laughing] she said, 'You're volunteerin', you're not bein' paid; this is stupid,' and when I collapsed that was it: she put her foot down [sound of horn beeping], if she could!

Facilitator. [Laughs] Mm.

Yes.

I didn't... [inaudible: object] To be honest, I think we began to lose faith in the chief execs, and there were things comin' back, that were just, we felt, were ridiculous.

[Break in recording.]

So now I'd like to discuss your parents and relatives. Right, what is your memories of parents or relatives, later on in life?

[Voices in background] Bein' brought up as an orphan from the age of two, and bein' put in care, it was 1951-52 when I met this boy called David Robinson who was a very bad cerebral palsy [traffic noise] sufferer, whose parents took an interest in me when they found out. And in December 1952, I came to Denton to spend my first Christmas in an actual house, cos up to this I'd always been institutionalised and I'd never been in a house before. So I met David and his mum and dad, and we had a very nice Christmas spent with them, and later on his auntie and uncle, they came my foster mother and father, and they would come to see me every month at the school, Bleasdale House. And some three years after, when I moved to Singleton Hall near Blackpool, they came to see me there, so I was virtually fostered but still under the care of the Lancashire County Council who the foster parents had to get permission every time to have me.

[Talking together] Yes, yes.

Facilitator: Mm.

It wasn't a foregone conclusion that I would be...

So did they offer to foster you?

Oh yes.

Yes.

Yes, but later on they wanted, or some of the family – they wanted, to adopt me, but unfortunately the Lancashire County Council said, 'No', and me parents must have signed the papers that I wouldn't be up for adoption, which was unfair because I'd 'ad no contact whatsoever: none. And I couldn't understand why, but that was it: Lancashire County put their foot down, and that was the way. I was very happy with the [foster] family, at the time. Can I go onto the grandparents?

Yes.

Have we time? Margaret and Jack, who was my foster mother and father, her mother and father were still living and we got on fine. They were just like me own [marriage] family: very warm, [talking together] very loving.

What memories do you have of your [foster] grandparents then?

Very happy ones. [Interviewer laughs.] They lived in a cottage, down what we called Town Lane [Town Lane, Denton] and a daughter, another Aunt, Auntie Marion, and Uncle Peter, looked after them at their home, and they had one boy, and we were just like a normal family. [Traffic noise. Voices in background.] It was great,

Both: Mm.

but sad because they didn't have the power, they had to get permission every time they wanted me.

Yeah. What are your memories of other relatives from outside your immediate family?

Well they, 'ad quite a few cousins outside that, and they just treated me like one of the family. You couldn't... in fact I think David and I were treated more like brothers: which, really, we were. [Voices in background.] May I have - ?

What memories do you have of your parents' friends?

Friends. I didn't meet a lot of their friends – only the ones that the foster parents used to work with – because where I was livin' then, it was a big 'hatting' town, there was about four hat factories and we just met them from time to time. And they always asked how I was

[Laughs.] Yes.

and when... The other thing which has quite amused me was when we came home for holidays. Some of the people would come up and say, 'Oh 'ello, are you home for Christmas or Easter? When do you go back?',

Both: Mm.

you know. [He and interviewer laugh.] I thought, 'Well why bother [laughing] askin'?' but this was it. I was part of a family and this was great for me cos I'd 'ad, up to this time, [aircraft noise] just nobody.

Mm. [Voices in background.] What family stories or other reminiscences do you remember?

I remember the first time that the foster mother and father took me to the Isle of Man. We got a train from Denton Station to Fleetwood, and they rigged me out a beautiful hat, jacket: green silk. [Interviewer laughs.] And as we were comin' in to Douglas Harbour, five o' clock in the mornin', and a seagull did it all down me jacket, [other two laugh] and the stain never come out,

Facilitator: Yes.

you know. But, we 'ad lovely holidays, always.

Have you got any more happy memories like that?

Yeah. I have, but it's very difficult when you're tryin' to... There were sad moments as well as happy, like any family would have.

Facilitator: Mm, yes.

Do you want to share any of them?

Well, I think I felt it, as well, when the grandparents [parents of foster parents] died.

Both: Mm.

Because me granddad had one leg off, because he was diabetes: now I'm talkin' about 1953, when diabetics it was really bad because there weren't the modern drugs, it was just insulin.

Both: Mm.

And I think 'e 'ad to 'ave it twice a day. And gradually he lost his, I think he'd already lost his legs, or a leg, when I met him but, they were great. In fact he used to stop overnight sometimes, like any grandpappy.

Do you want to go on to about how you met your wife, and how that changed your life? [Laughs.]

Right, yes, it did very radically because it was Joan. When I first came to Denton I 'ad to live, properly, after I'd been to trainin' college in Leatherhead. I came back to Denton to live with them and somebody came to the door one day of the house and said, 'Oh we've got an evenin' for disabled people: would you like to come?' [interviewer laughs] so I took it, well, 'Yes,' so I went, thinkin' it was just a one-off thing, and it turned out to be that it was a club for disabled, run by disabled.

Facilitator: Right.

All the policy makin' was done by the disabled, and Joan [Pat's future wife] at that time, as she is now, she was the secretary of 'Inskip League for Disabled People' that was started in Oldham in 1947,

Yes.

by three ex-servicemen who, at that time, any disabled person [traffic noise in background] had a job gettin' into any normal clubs,

Both: Mm.

you just

No.

weren't accepted, and this is why they formed a club.

Yes.

Anyway [voices in background] I went, and at the end of the evenin' I went home, and me foster mother said, 'Well, how did you enjoy it?' I says, 'Oh it's great'. I said 'It's a club for disabled, run by disabled, you know.' I said, 'But by gum,' I said, [interviewer laughs] 'there's a secretary there,' I said, 'Ee, I wouldn't like to marry 'er!' [Other two laugh.] Just like that, I said, 'Oh gee, she's a right thing.' Anyway, eventually we found out that we 'ad a lot more in common. There were quite a few years' difference between us but that didn't matter, and so in 1962 we decided to get married, and we were married on 21st December, 1962, four o'clock wedding, the Full Monty: Nuptial Mass. so we didn't come out till about half past five, and then a friend of ours from the club was takin' all the weddin' photographs as a weddin' present, but unfortunately, something went wrong with his camera,

Oh dear.

and the local paper photographer turned up, and Joan said, 'What 'ave you come for?' So he says, 'Oh I've come to cover your wedding, because yours is the first disabled couple wedding that we've in the area, so it's big news.' Well, this was a new church bein' built from the old – a brand-new buildin' –

Facilitator: Right.

and somebody a'd been tamperin' with the thermostat,

Oh yes.

and this was in the foyer, and they put a notice on top of this thermostat: 'Please do not touch', and when the photographer's picture came out in the paper, front page, you could see this over Joan's head: [laughing] 'Please do not touch'. And it was a very cold night, it was icy, but the wedding was marvellous. We got one or two comments but that's what we expected. Nice wedding. We went to Joan's cousins in Marple, for our honeymoon and, nice, just nice, and then in 1963 Joan was expectin' our daughter, Ruth, and she was due to be born in the August, but she was in a hurry

to be born, and she were born on August 16th and which I was surprised because Joan was havin' a caesarean birth, and with it they told her she 'ad to hang on. Anyway she was two months' premature, and they 'ad to, well then. And she were three pounds two [ounces] at birth, and went down to two pound 14,

Wow.

so we got comments about that, 'specially when I went to Dunlops Rubber Works in Manchester, they couldn't believe that, first of all I was married, and that we'd got a daughter. [Sound of siren, plus voice.] So they said, 'Well, how did it happen?' so I said, [interviewer laughs] 'What d'you mean, 'ow did it happen?' I said, 'We're a normal couple.' 'Normal? You 'aven't got a daughter,' I said, 'I have,' so they said 'Yeah, well how?' so I got a bit edgy on this, so I said, 'I'll tell you what,' I said, 'We 'ad an arrangement with the bread man, and 'e used to come every mornin' [interviewer laughs] at eight o'clock, to lift me on,

Yeah.

'and then 'e used to come back at night to take me off,' and I said, 'One mornin' 'e forgot to come back, and that's how we've got a daughter.' They was not amused, but that's my sense of humour,

Yes, yes.

and that's the only way to treat it, you know, cos some of the questions... it's unbelievable.

I can imagine. [Loud noise of plane.] Have you got any more children?

[End of Track 3]

Tape 2 Side B [Track 4]

Right. So have you got any more children, or any more grandchildren?

We 'aven't got, well, we've just got the one

Yes.

daughter, because they said it would be dangerous for Joan to 'ave any more. And eventually Ruth was married when she was 19, and it was about four or five years before they 'ad any child. First of all she 'ad a daughter, our granddaughter, Hayley,

Yes.

and she's now 16 this year, [traffic noise] and then two or three years after, she had Matthew, that'll be 12 this year. Beautiful, grand, we're a very close family, they can't do enough for us, without bein' over... [Voices in background.] They're very good to us. Me son-in-law, he's disabled, but that was at school when he was nine – the teacher made 'im jump over the vault and 'e didn't want to do it, and 'e caught 'is spine.

When your daughter was young, did you get any help with her?

No, because Joan and I 'ave always been very independent:

Mm, yes.

that's the way that we were. Although I went to two special schools for handicapped, we were made to do most things for ourselves, because their theory was, you know, you can't rely on people: the more you do for yourself, the better, and that's our policy. I think they're far too soft nowadays, you know.

Yes.

Facilitator: Mm.

We was always taught: 'There was no such word as can't.

Yes.

'Try it first, then if we think that you're havin' problems, then we'll help you, but ...'
I remember 'avin' to... I even helped one or two things in, to feed them or to wash
them. They never wanted me to do it, because I used to, particularly washin', get
soap everywhere, where it shouldn't be.

Facilitator: Yes.

[Laughs.]

'Oh it's in me eyes!' 'Well shut your eyes then.' [Other two laugh.] 'Oh it's in me
mouth!' I said, 'Well shut your mouth then.' [Laughs] This was, you know, they used
to, you know, but -

So what memories have you got with your daughter, when she was...

Very happy.

... when she was growin' up?

We didn't have any problems [interviewer starts to say something] but when she went
to school, and she had one or two then, but she never told us. It was a mother of
another girl who we were friendly with, and she heard this certain girl say something
to Ruth, but Ruth would never tell us: she was very protective that way. But she
remembers one day; she was in the secondary school, and there was a lad there [traffic

noise] who were foolin' about, and the teacher said to 'im, 'Sit down,' he said, 'you're actin' like a spastic.' And this – Ruth's friend – she said, 'Excuse me sir, but Ruth's dad is a spastic, and that is insultin'', and, to me, obviously then, it was not a thing for a teacher of a school to come out with,

No.

because we had problems. This was why we were so adamant on havin' the name change, [from 'Spastics Society' to 'Scope'] because it had many wrong impressions: it virtually said; if you were a spastic, then you was also mentally-retarded,

Yes.

and it was far from the truth where I was concerned.

Both: Yes.

I think the education we had was limited, and we've done well, because it wasn't just academically... we had to be taught how to dress ourselves, feed ourselves and eventually, get ready for the outside world. And I vowed then, in a early age, that if I could possibly help to make things better or to make people understand, I would, and that's what I've done. In a lot of ways I think I've been able to do this.

Have you got any more memories? Did you say you've got a granddaughter?

Yes.

What memories have you got of your granddaughter when she was born,

Oh.

and how does she react to your disability?

Well, do you know it's a thing that never enters the... they just cannot visualise us bein' disabled at all. It weren't the granddaughter but the grandson, and there I'm going back, what, four or five years ago, when you, you know, he was very young, . Joan had artificial limbs up to five years ago. She walked on these artificial limbs, and of course yer skin's goes funny when you get a bit older and she began to get more and more blisters on her stump. So it was either leaving them off or she could 'ave finished up with gangrene, and so she took the decision that she could no longer wear the limbs. And one day, Ruth, me daughter, said to Matthew, 'We're goin' up to see Grandma Joan, but she won't 'ave any limbs on: any legs,' cos 'e'd always seen 'er with legs: never seen her without. So Matthew came in, and Joan was sat there in her wheelchair, and 'e said, 'Ello Grandma!' So, 'Ello Matthew.' 'No legs,' [aircraft noise] and Joan said 'No.' And she wondered what 'e was goin' to come out with next. He said, 'Never mind, you've got wheels.' [Interviewer laughs.]

Facilitator: [Laughing.] Yes.

I'm right, you know, they've never mentioned... they don't think that way, you know. To them we're their grandparents, full stop, there's no... And Hayley – if anybody said anything funny, it'd be God 'elp 'em, [interviewer laughs] you know, because she just does not... they're not protective, but they don't think of us as bein' disabled at all, it just doesn't enter... Like Ruth, she never even, because I remember we was once invited to the Red Cross holiday in Blackpool – it was the fiftieth year – and there was a man down there, had all his face and that were burnt with steam: a thing 'ad blown up and hit him.

Facilitator: Right.

And now, why he picked on us, I don't know, but he used to come every mornin', and Joan used to just fasten a shirt button for him. Our Ruth said, 'I wonder how he manages at home,' and Joan said, 'Well, how do we manage?' and she [Ruth] just turned round and said, 'Well you're different.'

Both: Mm.

And that's the way it goes, and that's the right way cos you don't need sympathy. All you want is a bit of support,

That's it, yes.

and treatin' normally.

Facilitator: Yes.

I can't understand people, the way they think.

Facilitator: I can't.

OK. That's very interesting. I'd like to again go on about your home life, and where have you lived as an adult?

Basically here. All these were when I first came to Denton, all these were prefabs, and when we were married we lived in a one-bedroom flat nearer to Denton, so of course when Ruth got to a certain age [voices in background] she had to have a room of her own. And these prefabs were the only accommodation they could offer because, you know, even in 1960 there were very few adapted houses. So of course we came, I'd already been married from the prefab anyway, so they were no different to me, and I think Ruth was 11 months [old] when we came up and, you know, we managed. A few things we might have done unconventional but it doesn't matter, so long as you get to it. [Interviewer starts to say something.] She was very... [laughs] I remember one day, I was in between jobs, and it was a February, and when she was very young she always wanted to go out: [interviewer laughs] always, and we had 'o gate her, [keep Ruth behind a gate] and one day Joan says, 'Right Ruth, you're a bit older now,' she said, 'when you go out, you must keep hold of the thing.' And one mornin'

she only 'ad her pyjamas and house coat on, and the next thing I knew, she was 'alfway up the avenue in her pyjamas. [Other two laugh.] And there was a bloke on a ladder cleanin' the lamp, [laughs] and he caught her and he brought her back. And another time, I don't know what had happened, but she got out, and Joan said, 'Right! Come back here!' She [Ruth] said, 'No.' She said, 'Right wait till I come out,' because Joan did not believe in tellin' me, 'Wait till your father comes 'ome!', : [interviewer laughs] any problems, she solved them herself,

Facilitator: Mm.

Yes.

because they've forgotten by the time you come home. And she's stood on the thing, with 'ands round her hips like that, and she says, 'Well I might as well come and 'ave it now.'

Facilitator: [Laughing] Yes. Yes.

And that's the way, you know.

Both: Mm.

She couldn't see the disability whatsoever.

That's good.

But she's a corker now. You know, very carin', like the rest of the family – they're very carin' without bein' over the top.

Facilitator: Yes, that's good.

What effects has disability on payments had on where you have lived?

In the past, just a bit, but gradually as I got into more and more voluntary work, I got in and I've helped to make people, with others, helped them to make them understand the problems, and the way that they push the... [inaudible]. [Voices in background and engine noise.] Like the lack of housin' for disabled people, that was a big issue, and one of the biggest achievements was transport, or the lack of access onto public transport.

Yes.

This is why I joined. I was on the Transport Users' Consultative Committee for the north west of England, and that covered from Crewe to Carlisle, so you could see it was a massive area that we covered. This was a government appointment. We was appointed by the then Minister for Trade and Industry, we didn't get paid we just got our travel expenses and a meal. [Knocking sound: voices in background.] and I was subsequently on two big enquiries: the Heysham-Belfast [enquiry into the closure of the Heysham to Belfast Ferry Line]. When that was held in Morecombe Town Hall some of us got threatenin' letters: what would happen if it went ahead? We were searched goin' into the hotel across from the Winter Gardens, and they'd got Ian Paisley over [interviewer laughs] as an objector. He didn't get his own way, the Chairman in the railway thing said, 'Right, good mornin' Mr Paisley, you've got exactly 10 minutes to make your point: there's other people to hear,' and dead on 10 minutes, [laughing] she shut him up, and he went. And the second one was [voices in background] the 1986... the Leeds Carlisle big enquiry [Leeds-Settle-Carlisle line]. We spent six weeks goin' right from the... We didn't cover the Yorkshire side because they 'ad got their own, but we 'ad a joint report and we saved the line. And one of the objectors was Barnes Wallis's son: you know, the one that invented the bouncin' bomb?

Both: Mm.

Well his son – cos he used to work for [sound of cutlery clanking] British Rail at one time,

Both: Yeah.

and fell out with them. And it's very interestin' because we even got to know the sex life of a bee, on the moors of Yorkshire. [Other two laugh.] Very roughly, you know. A lot of it was repeatin' it all, but the thing is we saved it, and now they're doin' all the stations up. [Voices in background.] Education: when they were talkin' about pupils, disabled, bein' integrated into normal stream education, I 'ave always 'ad reservations because I don't think, through experience mostly, that you can integrate every disability, it's just not on – particularly if you need speech therapy or physio, it just disturbs the rest of the class.

Yes.

But I, still to this day, am not convinced that it wholly works because it's not in the infants or the secondary, it's when you go on to further education, and when you've got these tower colleges. Under the fire regulations, they're not supposed to go above the third floor. Now the subject that you want could be on the sixth floor, you know, and you're just not able to follow. So that was a good example where my experience came into it. I think we've progressed. I think the internet now, particularly with the Open University, will 'ave eased a lot of it. [Laughing.] That's if they can afford the fees.

How would you describe your place in the community, or sense of community?

In some ways, I think we've gone back: we've gone two steps forward, and taken so many back.

In what way?

It's all down to money now,

Yes.

today. You know, with the ser... I'm not political, this isn't... with the cutbacks and services, and I don't know about your authority but the disability bit of it is just mostly on the 'back burner'. I mean it's not for the want of tryin' because we had a good planning committee where we used to go and look at plans every month, send our recommendations in. Environment: funnily enough, we once did a survey of public buildings, and we went to a church and a bloke came out and said, 'What are you doin'?' I said, 'We're suveyin' the church for access for disabled'. He said, 'Well d'you think you should be on private land?' and I said, 'What d'you mean?' He said, 'Well this is private land, is this church.' I said, 'Excuse me, but the church belongs to the community. There's no such word as 'private', and we've as much right to be able to come into a church as anybody else.'

I agree there. So do you think you are valued in your community, like in this area?

Yes, I am. [Laughs.] Yes, I am. Not just meself – the people I work with. And I don't mean this in the voluntary sector. I can see better things since we've started, like we've always made sure about dropped curbs. We've always been reluctant about these when the central governments have brought these disabled right things out because, particularly one we thought. We called it, 'the fishnet thing', because it had more holes in it than a fishin' net. And even now, although every buildin' is supposed to be made accessible, their interpretation of access and ours are completely different. They just think, 'Well, if we put a ramp outside, with railin's, you've filled the criteria.' Well you haven't, because you've got to also think about the buildin' inside: particularly librairies. I mean, if you go into a library, the book that you want can be on the top shelf. It's no good people sayin', 'Oh well, you've only got to ask,' – that is takin' yer independence away. That's not what we've been fightin' for. We've been fightin' for equal rights.

Did you ever use the DDA [Disability Discrimination Act] as a tool, when you challenged people?

Sometimes.

[Interviewer still talking.] Yeah, but a lot of people didn't know what you were on about, basically.

I mean in these days, like if you can't get into a building...

You see it's difficult, but I mean we had... naturally, we do mention... but, like this town or like most towns in the Tameside area [area of Manchester], you can be talkin' about Victorian buildin's and there's a lot of times when it just isn't feasible, and I think you've got to learn to comprise sometimes.

I agree.

I know it's not -

[End of Track 4]

Tape 3 Side A [Track 5]

[Someone whistles under their breath.] Facilitator: Yes.

We've got a very good... The main town for, is Ashton-Under-Lyne. Now they had a lift in there up to two years ago... or, no four years ago... that allowed you to go to every level. And then all of a sudden, through the DDA, they decide to spend money on puttin' a new lift in which only took you to the first floor, and then you'd 'ave to walk round the corner, [interviewer laughs] then another lift... but this new lift had no back to it.

Facilitator: Right. [Interviewer laughs.]

So at the back, it was all wall. And what you had to do, you had to keep your hand on this button.

[Laughing] Yes.

If you take your hand off the button, the lift stopped. Now anybody with arthritis, or even cerebral palsy, you've got problems, until we said it was a danger. In fact a woman had a fit in the lift when she was in on 'er own,

Facilitator: Right.

and the lift she nearly lost her arm, because if you were goin' dizzy what's your normal reaction? It's to put your hand out to 'old: not if the wall were movin'. So she finished up [Pat presumably demonstrates]. So we've 'ad a small group in... every year the ladies were invited to the Mayoress's do, and we refused to go now because we feel that it's a danger, and the health and safety, and we've tackled the authorities about this.

Facilitator: Yes.

Mm.

Not interested. But other bodies, and they've told me: 'Well, we've put this lift in and we're not movin' it,' and we've even had the DDA, the disability thing, on it, and we've 'ad no joy. So the only way we could protest was to say that, 'Sorry, we can't use the lift,'

Both: Mm.

you see? But we've not got others doin' the same.

Facilitator: Yes.

I mean there's disability and disability. And we've got a very big majority of elderly and it's a vast difference between, say Joan and meself and the person next: probably got something through age. And this is what you're up against. 'Oh we're disabled,' but they're not. Most of them, it's because of age, it's nothing to do with things like ours. I wanted to say, 'Well, if you want to get your hand chopped off then carry on!'

Facilitator: Yeah.

And that's what it's goin' to take.

Facilitator: Yeah.

Mm.

Somebody's got to be injured seriously, before anything's done.

Facilitator: Yeah.

Both: Mm.

Right, now I'd like to move on to daily livin'. [Banging noise.] We would like to explore the routines of daily life needed to get ready for, and to progress through, a typical day. How would you describe a typical day?

[Pat and interviewer laugh.] It's a good job we didn't 'ave Candid Camera in our bedroom in the mornin'. Particularly when Joan had her limbs, because, can you visualise... Joan sat on the bed tryin' to put her limbs on, on this side, and I'm on the other side, trying to put me socks on. Can't see me foot, tryin' to put me socks on. [Laughing.] It's hilarious.

Yeah.

Proves you've got to see the funny side.

Oh, yeah!

Now it's different because I 'ave been quite worried for quite a few years about the aging problem of a person with a disability. And I brought this forward once at a meeting when Alpha were goin', at a Chairman's meeting of Alpha, , because I thought in a lot of ways, when you get older you're also goin' through the aging process, but people don't see that way – they just see you've got a disability, and they're forgettin' that you're also gettin' the aging problem. And I brought this forward, and eventually they got a doctor to publish a booklet on the problems of aging, cos I remember, I don't know whether I mentioned it earlier, four years ago they 'ad to fit me with a catheter, because I'd started with prostate... [laughing] that is another aging problem

Facilitator: Yes.

of a man. And they did the operation twice and just said, 'No,' they said, 'we're goin' to 'ave to fit a catheter.' So this was on a Wednesday mornin', and the nurses said, 'Right, we're open from eight till five every day, not on a Saturday and Sunday, so if there're any problems you've got to go to A&E [accident and emergency].' So the first night I'm wet through. They mustn't have fitted it proper. So I said to Joan, 'Right, I'm goin' up.' [Joan?] changed me and I went up. So I drove up in me car, waited two hours, nearly, to see a doctor. When I did see the doctor, the first question she asked was, 'How did you get here?'

Facilitator: Oh, mm.

I think I mentioned that.

Facilitator: I think you might have mentioned something.

Anyway, it doesn't matter. So I said, 'Oh, in a car,' so they said, 'Who drove you?' I said, 'Nobody drove me, I drive me own car.' 'Oh! What nursing home are you from?' [Interviewer laughs.] I said, 'I beg your pardon?' I says, 'I'll 'ave you know, I've lived in the community

Yes.

until, from the age of 11.' 'Oh,' and I said, 'My home is 11 Roe Lane in Denton, which is a bungalow.' [Interviewer laughs.] So damn me, she said, 'Right I'll go and get the sister to fit another one.' She were goin' to get me old sister, and if she didn't come out with the same questions. I said, 'Don't you lot look at anything?' I said, 'Look, two years ago I was asked by the health authority to loan a disability awareness pack.' I said, 'Haven't you read it, [interviewer laughs] or can't you read?' I said, 'It's there to learn yer about disabilities. Ooooooh!' [Facilitator laughs.] Now I'm not medical, but it's things like that – they

Facilitator: Mm, definitely.

don't listen.

Facilitator: No.

In adulthood, what contacts have you had with health services: the social services and with care services?

[Laughs.] Right! I mean I've always been on the social services, right from a child, and then in 1974 I was voted onto the Community Health Council until years ago they abolished it. And we used to go round every department of the hospital to see whether... and it was amazin' when we were goin' round – the lack of information that was bein' put through. We had a friend who was partially sighted and had a dog with him, and he went to this window and 'e said to the young lady, 'Can you tell me where such a department is please?' To which she just said to 'im, 'Follow the yellow line,' and this is a blind person! [Interviewer laughs.] So 'e turned to the dog, 'e said, 'Ey, follow the yellow line.' Mind you, they won't admit it: one is totally blind and they 'ad a habit of puttin' a drink or their meals on the locker, and walkin' away. And they'd come back and they'd say, 'Oh, you haven't had your meal yet?' So this person said, 'No, because I didn't know it was there.' 'Oh,' she said, 'why?' She said, 'I'm blind, I'm totally blind.' 'Oh, I didn't know that.' And they should be taught. And this is this day and age,

Facilitator: Right.

not long ago.

How do you think the view towards disabled people have changed, compared to your childhood?

Well, of course they were treated like nutters [all laugh] for one thing, because we were like the pilot school: there hadn't been any school like it before, and [interviewer

laughs] we used to get doctors, and social workers... It makes you wonder my head isn't flat, [interviewer laughs] well, with bein' patted on the head. 'Oh, been a good boy? Oh, you are clever!' And unfortunately, well one day I got browned off and put on the board, [interviewer laughs] 'Welcome to the zoo,' [other two laugh] you know what I mean? [All laugh.] So, the swine...

Facilitator: Yes.

I was just,

Yes, yes.

you know,

Facilitator: Irritating.

Yes, yes. [Laughs.]

And, I must add, I must say Scope were the worst offenders,

Yes.

they really were.

Both: Mm.

You know I mentioned why we made sure that a lot of people with cerebral palsy got on the bigger committees.

Yes.

They were just, horrendous.

Facilitator: Yes.

I mean 'alf of them didn't know what cerebral palsy was. I mean, I was asked would I do a survey, Scope were doin' a survey, , and they'd got an outside body to do it, and she came here and she sat down, and she said, 'Oh, have they found a cure for thee yet?' I said, 'A cure for what?' [Interviewer laughs.] She said, 'cerebral palsy.' I said, 'aven't you read; haven't you done your 'omework?' I said, 'You're born with it.' 'Oh.' 'It's an accident durin' birth: you can't reverse it.' 'Oh.' I thought, 'Oh my God. Give us a...!' Why Scope didn't do it themselves, I don't know, but they spent all this money on this thing and we're no further forward.

What has been your experience as a consumer or customer?

[Both men laugh.] Well, [laughs] I must be the... I have home care come twice a week to help me in and out of the bath, although I've got a [?]. I have problems with puttin' me legs, over the bath,

Facilitator: Right.

and it were very important that – when you wearin' a catheter – you do have at least two or three baths a week, to cool down the infections. So I've 'ad this now for about three years, and this last time I was in hospital seven months, and believe it or not, while I was in the hospital, they were still chargin' me for somebody coming here to give me a bath.

Facilitator: Blimey.

The bill came. I was in and I was getting ready to be discharged and it took 15 days to get the hospital social worker to come and see me about what I would need when I came home, so I told 'er I just needed help getting in and out of the bath, so she came half an hour before I was due to be discharged. So when I got home, we got a

telephone call from the home care cos Joan has a cleaner twice a week and the one in the head... The home care services: 'We've 'ad a request from the social worker at the hospital and he said something about Mr Entwistle needing a shopper,' and we said, 'That's not what we said. We need somebody to come and help with the bath,' and we had a heck of a job getting put right.

Yes. Can I just ask; are you able to access direct payments in this area?

Yes. Yeah, well you see there again, all depends on the social services. They 'ave to pay for this, and if they haven't got the money... I mean we did the, oh, I belong to the Thameside Forum of Disabled People, and when they were settin' up the payment thing, we did all the work:

Yeah.

negotiations, you know, and we set it up. And then, it was alright, and then there were some clients who weren't getting, although they needed direct payment, social services were coming back saying, 'No, we've run out of money,' and that's when, you understand, everything else 'as always had cut-backs. It's still goin'. We still ain't getting direct payments. We found that people, or disabled people, was only coming to us when they needed something, and directly they got what they want, you never saw them again, and we just said, 'Well this is not on: we're not goin' to be mugs any more.' Same [?] services, they only want you till they've got what they want then, disabled people, are just on the [?]. Their priority now is the elderly: and I'm 'appy to join them. [All laugh.]

Right. How has physical access to buildin's and services changed?

It varies, dependin' where you live. Public buildin's are a headache, they really are,

Yes, yes.

particularly libraries, town halls,

Yes.

because as I said before you're dealin' with a lot of Victorian. I know we shouldn't be makin' excuses, but when you go round, I mean you've got to be realistic because particularly with social services, they'll say, 'Well, if you want that, you can't 'ave this,' which, we're due a prioritise: and you can't speak just for yourself, you've got to speak for other disabilities as well. This is why I'm a very big believer in the born-build houses – these houses that are built from cradle to grave. But there isn't many authorities, tenders. Derbyshire is the best. They're the best authority, regardin' disabled, without a doubt. What they've got here is magnificent. You know, it's...

Yes. OK, now I'd like to discuss your leisure and social life. What have been your favourite leisure pursuits, such as readin', writin', or entertainment? Or what do you enjoy doin', what sort of thing?

Well I mentioned this club called Inscape: this is purely a social club, and we don't deal with people's private life, we're just there to enable to 'ave a social. It's a club where we probably get an artist or we play bingo, or we 'ave quizzes: we 'ave mostly quizzes – get our brains stimulated.

[Laughs.] Yes.

And up to this year, we've been goin' on holiday together to Skegness, which is marvellous – it's flat and the people there are marvellous. We 'ave the Lincolnshire Red Cross who come, and they act as enablers, I don't like the word 'pushers', it sounds like they're pushin' drugs, who take us out in wheelchairs durin' the day, and then they'll help anybody who needs help, dressin' or, undressin' and washin', , and we 'ave a good time. But unfortunately the club itself; the members have been dwindling, and we've got to a point now where it's getting too expensive just for the coach alone. We have an adapted, or we don't but the Greater Manchester PTA

[Greater Manchester Passenger Transport Authority] 'ave a coach adapted with a lift, and I was billed for a day out in September to a shopping place in Wales, and that's about £200 a day. So, you know, you've really got... and that's only for about 20 people, so I think you've got to start thinking about the cost.

Yes.

And going to Skegness, that is just under a thousand just for transport.

How has impairment affected your leisure time?

How's?

How has impairment affected your leisure time?

Well, not a lot because we've had a mobility car for, what, 30 years. It's only till recently that, as far as I'm concerned, the problem has started because 'avin' to lift the wheelchair in and out of the car. But luckily, again, Joan bought two chairs, one to use in the house and one we keep in the car, so there's not... Although with this illness we've not been anywhere: well me daughter and me granddaughter, they've done all the liftin' and they go with us shoppin' and that sort of thing, but up till then we just led a normal life. We've been on holiday, we've gone out in the car. In fact one day we drove from 'ere up to Marsden. We used to sit in the car park at Marsden. And I've even made it to Sheffield. Not again. I weren't keen on Sheffield. But no, not everybody is that fortunate. You know I think it's harder if you've got to rely on somebody drivin' you: you're very reliant on them. But if you can drive it's much easier and you're independent. But, now I don't think it's as much me disability, [someone coughing in background] I think the biggest majority is the agin' part and with this problem which I have now. It's nothing to do with cp [cerebral palsy], it's just one of those things. It's funny, I could accept me disability, but this I've had...

[End of Track 5]

Tape 3 Side B [Track 6]

What are your best leisure experiences, and worst?

Leisure: for many years I tried to swim, but I just could not get the coordination right. I'd get me legs goin', and then me arms'd stop, and I think a lot of it 'as been fear of water.

Yes.

I once said this at school and the man said, 'Well you look very clean, if you don't like water.' [Laughs.] But other leisures: we like goin' out to historic buildings, houses, but you see there again you are restricted on how far you can go. You probably can only go on the ground floor, or the drives will be made up of shale and you know what it's like tryin' to push a wheelchair over small shale, and when you bring it forward they say, 'Well, if [it] were tarmac, the buildin' would lose its character.'

Yes. What's one of your worst experiences, in relation to leisure? Or something that you wanted to do, but have not been able?

Oh, swimmin' for one, because I think everybody should learn to swim, and the sad part about it is swimmin' actually is the best therapeutic thing you can have. It relaxes your muscles. It's disappointing that I've tried and tried but... I know we used to go to our local baths on a Tuesday night, and me daughter were with me. Well even Joan used to swim with arm bands on and she could swim like a fish, and one night I was in the bath and I said, 'Oh look, I'm doin' it,' and me daughter said, 'Right Dad, now take your foot off the bottom of the bath.' [All laugh]. You know, really for leisure, and I must be honest, when I was in the voluntary I didn't get much time for leisure, and in a lot of ways I regret it because a lot of this trouble that I have now I think stems from the hours that I spent for other people, and I think I pushed me body beyond, and it's taken all these years to realise. I mean Joan would say, 'You can't

keep this up: you'll just collapse,' so now I do a lot on the computer: sendin' emails to friends, but it's costly. And I save post cards, about 800. One of the Titanic, one of the Vanguard,

Yeah.

That sort of thing.

Facilitator: Wow.

What memories do you have holidays and holiday destinations?

Oh holidays. Well, you name it, we'll find it. [Laughs.] Lovely caravannin'. The Greater Manchester Cerebral Palsy Society have four caravans on Robin 'ood, it's now Lyons, [Lyons Robin Hood Holiday Village] and, well me daughter was only, I think, four or five when we first started goin'. You could tell there was still the stand-pipes and gas mantles when we first started goin' and it cost me a fortune on gas mantles. And we've been to one or two holidays, and the one we used to go was [?] Sands, and we had a few problems with the caravan. Not with the caravan themself, but the people that was using [them before] were disabled, but they hadn't been cleaned properly, and you could always smell the urine, some way. I know disabled people can't help this but I think, you know, there were no need for that. So we decided to go in one of their small bungalows that they had. Well you see Joan wasn't in a wheelchair then, and then when Joan became permanently in a wheelchair they weren't suitable, because there weren't much room for anybody in a wheelchair. So I wrote to Rank, who own the camp, and I didn't get a good response. So I said, 'Right, that's it, we're not comin' again,' but I'm 'opin', through the DDA, something will be done. They're goin' to 'ave to do something,

Facilitator: Yes.

because it wouldn't 'ave cost them anything to do at least two bungalows with wider doors, but no they weren't. So I says, 'Right', so, 'Oh!' they said, 'Well it wasn't a camp fit for disabled people,' and I said 'Look, you've taken our money, we've been three years on the run,' and I said, 'It's not for disabled?' I said, 'And yet you've got three caravans for disabled people?' I says, 'You can't 'ave it both ways.' [Other two laugh.] Anyway we didn't go back again, so since then we've just been to Robin 'ood. and now we've been away with the club, and at the end of August we always go to the farm outside Keighley,

Facilitator: Yes.

which is wonderful, looking over Ilkley Moor; and it's a working farm. They 'ave cows.

Facilitator: Ah.

They're not milkers, they're beef cows, animals. And we've been goin' 18 years and we meet up with these friends from Marlow from England, and we virtually take over the farm that week. [Other two laugh.] You see they [?] because the owners, the two sisters they had a brother, which was the oldest one, and he 'ad cerebral palsy.

Oh right.

And every now and again you'd [engine noise] 'ear Jean, one of the sisters, say, 'Hang on, we're tippin'.' I'd be upside down and chokin'. [Other two laugh.] Oh it's marvellous. We've even got a CD-ROM on it – a friend of ours takes his camera and 'e done this CD for us.

Oh that's good.

Unfortunately, we've loaned it out to somebody and we've not got it back yet. We must get that back cos we met [rustling noise in background] a family; a mother and

father and a daughter from abroad and they come over to see a specialist about a walking aid, which is so that the girl could learn to walk...

[End of Track 6]

Tape 4 Side A [Track 7]

Hi, Pat. It's nice to see you again.

Yeah.

I'm sorry it's been so long. In this section I'd like to start discussin' contact with other disabled people? Is that OK?

Yes, yes.

Right. How would you describe your contact with other disabled people?

Well this really started back in the late 1940s when I first went to Bleasdale House, Silverdale, and this was a special school for physically handicapped boys, and this was a school for multi-handicapped. At the time, there was about 24 boys with all kinds of disabilities: cerebral palsy, haemophiliacs, hole-in-the-heart. You name it we had them there. So really it goes back quite a long time and it was the first time that I really realised that I wasn't the only handicapped lad on earth. Anyway, it was a shock to see some of them, but you get used to them, you learn to help one another. Since then I went to the secondary school that was opened in 1952, Singleton Hall, just outside Blackpool, where the boys were from 11 to 16, and this again, I met all the lads with [noise of aeroplane] different disabilities, and I think you just learn to realise about other people's difficulties, and learn.

And do you still keep in contact with them people?

Yes, I'm in contact with quite a few of them, but now there's a lot died off because we're talking about muscular dystrophies. In those days they were very lucky if they lived above 60 years of age because, as you know, muscular dystrophy is wearin' of the muscles and gradually, if they get a bad cold or pneumonia they're unable to fight it. So of course it was very heart rendin' because you'd see them go to hospital and

they never came back. And what made it worse, we had one or two, where there were two or three brothers, with the same thing. It must have been hard for them, to see what was comin' to them, because they're walkin' to school and they gradually finish up in a worse state, and they must of got that weak they won't be able to feed theirselves or anything.

[Traffic noise in background.] What has been the effect on your life of these organisations? Like Scope organisation, any disability organisations...

It's made me more determined to fight for the rights of disabled people, because, like goin' back to me school days, we were still dealin' with the Victorian attitudes,

Yeah.

you know? 'You should be hid behind doors and not be seen by the real public,' and this is no way! I mean now we're a person with disability. I may not 'ave done things exactly the same way they did but what did that matter? So long as you got your goals.

Yes.

And I think, when I was younger we were more encouraged to do more for ourselves than what they are today, and that helped me. Although I may not have realised it at the time, thinkin' back, it's allowed me to do [traffic noise] what I've been able to do in the voluntary sector for over 40 years, which is [laughs] nearly a life devoted, but it's been worth it cos I can [both talking] see.

Yes, yes. Did you used to work for Scope in Manchester?

I used to do voluntary, and I started that when they set up the Alpha, and then the other thing then came, and I was involved with The Land of Druge which was when we went round junior schools talkin' about cerebral palsy, and tryin' to encourage,

particularly girls, to get immunised against rubella and the implications there were if you weren't immunised, which was difficult sometimes, particularly the Catholic Schools when there was their beliefs. But we managed, . I think I managed to do about 70 schools in the Preston area, within about six weeks. [Traffic noise.] Two or three schools a day, but you had to do this. But unfortunately, Scope decided that the money 'ad run out and they dropped it, because I wanted to take it further

Yes.

to the secondary level: because that's when you can really influence the children.

How has disability discrimination law affected your life?

[Pat and interviewer laugh.] Yes: excuse me laughin' but it's what we call 'the fish-net.' It's the fish-net thing because [interviewer laughs] there are more holes in it than a fisherman's net. I don't think there was really, from the government's point of view, commitment to it. There was always some excuse why this can't be done, that can't be done. I don't think it applies today, even when the legislation we have about public buildin's all been accessed. I appreciate we are dealin' with Victorian buildings which is hard to do, but there must be a way round it, and there 'as to be. I think we're not strong enough. The disabled group: very weak, unlike America, when they sat on the White House steps for six months [interviewer laughs] until they got what they wanted. They got legislation, they got equal rights and they didn't move until they got these rights. But in this country we tend to be all mouth but no doin'.

Do you think there's been any improvement in the last 10 years, of that?

In certain areas, yes, but I think well there's still a long way to go. I remember about 12 years ago I went with Nigel Smith, who was then one of the managers of the north west and they were having a three day conference in Brussels on transport, which 'as always been one of my thorns in me side. And I went over and even then we was at least 10 to 15 years be'ind the other European Countries. It was an eye-opener. I

spoke in Parliament at the time, and since privatisation, well, we call it 'deregulation', of the bus companies: it's gone worse again. I know there's a lot of buses which disabled people can get on in wheel-chairs, but [aeroplane noise] to me it's nothin' to what America... They don't 'ave to think about it, it's there. What 'ave we got to wait? Twenty, 30 years before they even get a small...? Same with railways, they privatised that.

Any more of that?

Education. When they were talkin' on integration into the main stream education. I've always maintained, there's always going to be a percentage of disabled children. You can't possibly,

[Talking together.] I agree there. Yes.

integrate them with all the deaf. I mean it's better now, with computers,

Yes.

far better than when we only 'ad [laughs] black-boards and chalk.

Yes. [Starts to say something.]

And I think attitudes 'ave, I know they've changed a bit, regarding when I was a child, they were more concerned about daily livin', and there was no such thing as takin' GCSEs. We'd never heard of [the] thing: further education was non-existent.

[Aircraft noise.] What do you believe to be the media image of disabled people?

[Laughs.] Slightly better because I think we're gettin' to see more disabled people within programmes

Yes.

than what there used to be, but we're still... [Traffic noise.] We lost a good programme off the radio, some years ago. It used to come on a Friday evening and this was a programme... oh, what was it called? Anyway they took it off the air, and it was a programme where disabled people could talk about issues or discuss issues, living issues, and it just disappeared. I don't know whether you watch it or not, but there's a hospital programme on a Tuesday night, and they've got a chappie there in a wheelchair. He's supposed to be a doctor. In fact I think I know 'im, I've met 'im over the years. But I still don't think that there's enough disabled people within television. Radio: you can't see them, so you can't really say, but I remember some years ago, when the BBC invited so many disabled to a studio to watch a programme being made, and they came up and said, 'Do you mind if we move you to a side room?' [Interviewer laughs.] You're upsetting the rest of the audience.' I wouldn't 'ave moved.

I wouldn't either.

No way would I 'ave moved!

Or me. [Laughs.]

And this is the attitude that I think you get. I think Channel Four have been the best, ITV's not bad, but BBC – I think their policy 'as stunk. I really do. I think it's very... I don't know.

[Traffic noise.] In what way do you think that this could be changed?

Again it's all to the disabled movement, you know? [Coughs] Unless the... [Coughs.] Sorry about that. Unless they have to do something directly for them, they're not interested, or they'll get interested if there's somethin' for them, and as soon as they've got what they want [traffic noise] you never see them again, and I think the

local authorities, there's a lot of excuses. Like at one time, we had disabled people sitting on the Social Services Committee, and then all of a sudden that disappeared. Money, again. It's all down to money, and in the end it's nowt to do with money. Policy. [Interviewer starts to say something.] Unless disabled people start really fightin' we're not going to get any where.

You know when you wrote your book, did you get any media covered?

No. I wrote to every ITV, every BBC studio. I went every radio, everything, and I got one reply back from, I think it was, Channel Four again, and they said, 'At this time we 'ave no idea of doin' it at the moment, but if we ever do, then we will contact you.' And this is about five years ago and I'm still waitin', so I don't think I ever will.

Did you get anyone from Scope?

No. I even sent... I weren't interviewed by DN [Disability Now, a newspaper published by Scope].

That is sad.

And do you know when I went to the Palace for me MBE, not one turned up? They weren't interested. You know I thought, 'Well here's a chap with cerebral palsy, the one that they are making their living out of.' That's the way I look at it, they're making a living out of my disability, [aeroplane noise] and they couldn't be bothered.

Yes. Maybe we could do this project on our internet site, about your project. We could promote your book because there is one or two publications in there. I will ask Phil.

Mind you, i'nt't five years [?] from what I knew.

It's only four years old. So when Phil listens to this... Is there any way we could promote Pat's good autobiography?

I mean I 'ad a stall at one of the AGMs [Annual General Meeting] in London, and I think I sold about twelve. [Laughs.] And that was their organisation.

[Aeroplane noise.] Yes. How would you describe how you feel about yourself?

Meself? [Laughs.] Well put it this way – I don't think, knowin' what I know now, [interviewer laughs] I don't think that I would put in as much effort into what... because I think underneath, a lot of this problem I'm havin' at the moment is... and this isn't just Scope, this is through all the voluntary thing that I've done. I think it's not helped. I mean Joan at one time was havin'... you may not believe this, but we 'ad to make a date to go Christmas shoppin' and it was just ridiculous. I was spending more time away from home than what I was 'ere, and I mean I enjoyed it, you know, it's been a really... but I now sit and think, 'Was it worth it?' Jettin' to and [fro?]. Your health...

So what's your opinion about the medical profession?

[The men laugh.] Oh them, they're -

That's the sort of thing that the public want to know.

Well let me just quote from them, that happened recently: I've taken in vomited the old blood, and it's about two/three years ago, and I've 'ad this problem ever since, and November last year I was taken in. And on the ward me son-in-law came up with me wife and daughter, and me son-in-law said, 'Do you mind if I go and see the sister on the ward, to see if I can find anything out?' So I said, 'No you go.' So 'e went and he said, 'Can you tell me anything about Mr Entwistle?' So she said, 'Yes,' and this was the sister of the ward, 'yes, you know he's got cirrhosis of the liver, don't you?' So Mike said, 'No.' 'Oh yes, and it's his own fault,' so Mike said, 'Well what do you mean?' She said, 'Drinkin'!'

[End of Track 7]

Tape 4 Side B [Track 8]

... So he said, 'And I've been married to 'is daughter for 20 years.' 'Well,' she said, 'he slurs his speech, and he walks funny.'

Oh no.

So Mike said, 'Well, he's got cerebral palsy.' 'What's that?' Anyway, they went to see [traffic noise] the consultant, because it was [?] and this is typical. We always, both Joan and I, say, 'We're glad we were born when we were,' because the things that happened in the hospitals nowadays, is absolute ridiculous. You're just a number, you know? So I don't know what is...

It's not easy. [Aircraft noise.] What equipment has been a help to you?

The bath chair that goes up and down,

Yeah.

because now, with me hips goin', I have a problem with lifting them over the bath. This is why I have home care twice a week, to help me to bathe. As I get old, we all get old. No, it's just that and also the knob on the wheel in the car. I mean, without that knob, I couldn't drive a car. There's little things like that, and it's helped me and it's allowed me to do what I've done. [Interviewer starts to speak.] I must say, there've been times over the years when I could have throttled Scope; [interviewer laughs] well and truly. It's unbelievable, some of the stuff! But, I don't know.

Is there any more equipment that you use,

The word processor.

or anything that makes your life easier?

The computer: definitely.

Yes. [Starts to say something.]

I mean without the computer I would never 'ave got that book done, because I started off on a typewriter,

Oh wow!

and I'd get in the middle of a sentence or thing, and I'd hit a wrong key and ooh!
Ooh!

Yeah, yeah. [Laughs.]

And The Greater Manchester Society, or no, the regional committee, through David Branch, helped me – loaned me a word processor on long-term. But eventually, I was able to get me own, [laughs] otherwise I would never have been able to do reports and...

Yes. Say that you've got a lot of money, is there anything else that would help you, that makes life easier and more enjoyable that you can think of?

Not really. It's funny but I've never been a person that craved for...

Yeah.

If I get anything, it's got to be useful, and it's got to be something that I can use. I'm not one of these that get stuff just for the sake of gettin' it: buyin' it and never use it. It's got to be useful, otherwise [aircraft noise] you might as well not bother.

How would you now describe your disability, impairment, to others, compared to you when you were younger?

How would I?

Describe your disability, or impairment to others or, compared to when you were younger?

Well, in a lot of ways me body's deteriorated but I wouldn't put it all down to disability. A lot of it is what we call the aging process, and this is, like I said before, this is one area which I feel Scope and have done [?]: looked at the agin' process. I know a doctor's written a booklet on it: but other than this, you've got to be... I think every GP, every person in the health service should be made to read it, because they just haven't a clue. They jump to a conclusion before they really look at an issue. I'm goin' through now what anybody within agin' is going through, and [traffic noise] this 'as got to be recognised, by the health people. It's no good sayin', 'Oh, it's his disability.'

Yes.

It's not: it goes beyond the disability. I 'ad this with me liver, it 'as nothing to do with disability at all: it's just unfortunate that, [laughs] I got the cp [cerebral palsy]. But, apart from that, it's just annoyin'. I'd got to the stage where I could survive on me disability but this, when I first knew about it, knocked me for six. I want an answer well, 'Why? Don't you think I've gone through enough without havin' this thing?' And it took 'em far too long to diagnose it: far too long. And they finished up sendin' the biopsy of my liver to St. James' Hospital in Leeds, and when it came back they just said, 'Well it's to do with the diabetes, which has done 'is liver,' so I won't have long now! [Laughs.]

Do you want to now go on to disability in aging? Then I'll give you a question, to get going.

I didn't catch that.

Do you want to start off with disability and aging now?

Yeah.

And I'll give you a question to get goin'. What sort of thing do you think Scope and the medical profession could do to improve this project? What sort of services could they provide to make life more easier for you?

Very hard that, because while I was in hospital the social workers were supposed to come and see me, and it took them and I 15 days to get hold of 'er, and she actually saw me on the day I was bein' discharged. [Traffic noise.] And the only service that I needed regardin' that was help in and out of the bath. 'Rightio.' [Interviewer laughs.] Get home, and when he comes out, the co-ordinator of the home care services rang up and said to Joan, 'What's this about Pat wantin' shoppin'?' Joan said, 'He doesn't want shopping, he wants some help with gettin' in and out of the bath: he doesn't do the shopping, I do it with me daughter.' And yet [aircraft noise] I waited 15 days to get that, and of course they 'ad to start from the bottom, so instead of havin' that service from day one, it was three weeks before anything could be worked out. So I 'ave no faith really, in the system. It's, you know...

Can you suggest any improvements that you'd like to see?

I'd like to see... [Pat and interviewer laughs.] I'd like somebody to sit down and talk and listen, instead of tellin' me what service I need.

I agree.

[Laughs] I think that'd be a good start. I mean, you live your life and I 'ave found out the more you do for yourself, [traffic noise] the worse you come off.

Yeah.

You really do. 'Oh you can manage!' You can't manage. [Aircraft noise.] It's terrible, when I could really knock that wall through, you know? I mean it's because they come out with stupid remarks. They waste money. I mean social services talk about cut-backs: they waste money and I can prove it. They don't listen. They -

Can I ask you, have you considered getting direct payments? [Traffic noise.] Do you know what that is?

Yes, I helped to set one up, [laughs.]

Oh sorry. [Laughs.]

in Thameside. That was another headache, believe you me. But that was another thing: we had people who are goin' onto direct payments and while we were goin' through the process of getting people on to this direct payment, they were comin', but as soon as we got their direct payment, we never saw them again; and to me this is a selfish attitude. They don't want to help anybody else. If it's not for them, then they're, they're not interested. Again, direct pay, there was such a difference between different areas, with direct payment. To me the best one was, or the best authority, the best one is Derbyshire. Derbyshire do things for people.

What sort of things do they do in their area?

They have somebody on every committee you could mention, and they don't take no for an answer. They fight for their people, because it was them that started the direct payments. They came over and we were talkin' about direct payments and we still 'ave got Thameside Forum of Disabled People. When we were talkin' about direct payments, they came over and they gave us their experience of how it was set up, the best way of doin' it, the best way of talkin' to the local authorities or social services,

because I don't know whether you know, it depended on the social services, whether the people got direct payments.

Yes, yes.

It's very hard to explain really because a lot of it, yes, has somethin' to do with the cerebral palsy, but that doesn't help it, but it's very hard to get it over to the medical profession, and the social services, and local authority. Not everythin' appertains to your disability. Arthritis has nothin' to do with cp. [Traffic noise.] Nighty-eight percent of old persons gets arthritis. I mean I've had arthritis in the spine since I were born, so that hasn't made any difference; well it's makin' a difference with the hips. And about 12 month ago I went to see a specialist about me spine and he said it were curving over: but you don't know which is appertainin' to age and what is cp, or pushing your body, because since I were born, and I'm sure you push your body to certain limit, heavy, and you go further because the more that people said [aircraft noise] to yer, 'Oh you'll never do that,' the more you thought, 'Well, I'll show you, you buggar. I'll show you I'll do it!' But at the end of the day, it's takin' a lot out of your body, and this is what I'm thinkin' happened, to me anyway, that I've pushed it too far, and I'm now gettin' the consequences. [Interviewer laughs.] Well, I think really if I 'ad it all to do again, it's not in me interest to sit back. If there's something to be done, you've got to do it.

I mean at the end of the day people get out of life what they want.

Yeah, I 'ave thought that but you're right: life is what you make it,

I agree.

and if you're goin' to sit back and rely on others, you're goin' to be very disappointed, because they only go so far: and you finish up... well, you might as well do it yourself as at least you know it's done. But I'm very disappointed that there isn't the people coming forward within the voluntary sector now. It's just hard work, and

you get committee weary. You go and you attend these committees, and you find they're all the same people every time. There's no new faces.

I agree. [Aircraft noise.]

I'm disappointed with Scope has decided to do away with the lot of their services.

Yes.

After all, spendin' all these years gettin' them, and when they've really conquered it, they shy away. I know it's money, but it's wrong.

[End Track 8]

[End of recording]