



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

Melvin Walton
Interviewed by Anne Pridmore

British Library ref. C1134/26/01-02

IMPORTANT

Every effort is made to ensure the accuracy of this transcript, however no transcript is an exact translation of the spoken word, and this document is intended to be a guide to the original recording, not replace it.

Should you find any errors please inform the Oral History curators:

Oral History
The British Library
96 Euston Road
London
NW1 2DB
United Kingdom

+44 (0)20 7412 7404
oralhistory@bl.uk

This interview and transcript is accessible via <http://sounds.bl.uk>.

© The British Library and Scope. Please refer to the Oral History curators at the British Library prior to any publication or broadcast from this document.

Interview Summary Sheet

| | | | |
|-----------------------------------|---|--|--------------|
| Ref no: | C1134/26/01-02 | Digitised from cassette originals | |
| Collection title: | Speaking for Ourselves: An Oral History of People With Cerebral Palsy | | |
| Interviewee's surname: | Walton | Title: | Mr |
| Interviewee's forename: | Melvin | Sex: | Male |
| Occupation: | | Date and place of birth: | Bedfordshire |
| Date(s) of recording: | 24 th March 2005 | | |
| Location of interview: | | | |
| Name of interviewer: | Anne Pridmore | | |
| Type of recorder: | Marantz CP430 | | |
| Recording format : | D60 Cassettes | Number of cassettes: | 3 |
| Digitised as: | 3 WAV files (16 bit 44.1kHz 2-channel, 1411kbps) | Mono or stereo: | stereo |
| Total Duration: (HH:MM:SS) | | | |
| Additional material: | | | |
| Copyright/Clearance: | Open. © The British Library Board and Scope | | |
| Interviewer's comments: | Mic feedback throughout the recording. | | |

Tape 1 Side A [Track 1]

OK

So you want me to.

We're going to be talking now a bit about your early years.

Right, a bit about my early years. Well as I look back at my early years – and it was quite frightening – I was very happy when I was living at home with my nan and my grandad. I was very happy living there and I lived with them for ooh a good 18 or more years ‘cos mum started work. And really my nan brought me up, so she helped me accept my life and encouraged me to do things as much as I could for myself. And I’d always try to do as much as I could for myself. And I used to love meeting people but I was always a bit sort of shy and didn’t know what to say but I used to just put a brave face on and make the most of it. One of the things that I always remember about my early years was, I went up the shops and I was scared of the noise of the traffic and all that kind of thing. And if I have to start accepting all those things... but I think the thing that always sticks in my mind about my early years was... I was settling down, I was doing really well, having a tutoring at home four times a week and they used to come in and help me with reading and all this stuff. And I was doing so well and then the authorities decided that – because they didn’t like spending that kind of money – I had to go away to a boarding school and that’s where my life really, really changed. And I didn’t like it very much at all then because I didn’t go away to boarding school until I was about; I think I might have been 12 or 13 when I went away or pr’aps even older – can’t remember quite but I know I was getting on a bit – and I went away to boarding school.

Can you tell me what the name of that school was?

Yeah, I certainly can it was Elmfield School, Harpenden. It was a specialised school and really I was scared out of my mind to go away to a boarding school and do that, it was really strange.

Did you get to see your parents and your grandma much?

Yeah, I used to what they called weekly board. I'd be picked up from school on a Friday and I'd go back on a Sunday evening and I always used to 'ate going back to school on a Sunday evening and I didn't like it at all.

Can you tell me something about... d'you think you got much of an education at that special school?

No, that's where I was just going to come to. In the years when I went to special school it didn't really do me any favours at all because I needed so much one-to-one tuition and that took me a long while to sort of take anything in. So really I didn't really learn a lot. I learnt more – believe it or not – when I left school to what I did when I... I didn't leave school 'til I was 16-and-an-half, the only... I think going to boarding school did for me was help me accept my disability a bit better.

Can you tell me when you were at school; did you have any specialised treatment like physiotherapy or things like that?

I used to get a bit of physiotherapy but they used to put these arm callipers on me and they used to force them down on my legs and stuff. And it was really quite frightening it was quite a frightening experience.

Did you have any operations on your legs?

No, I've only ever had one operation in the hole of my life, that I've been very lucky. I've had one operation on my eye for a vertical squint and that's all I've ever had to have in my life.

OK, thank you. Can you tell me something now about what sort of things you used to do when you were younger, in your early years, for leisure. Did you have any hobbies or anything like that?

What I used to like doing when I was younger, 'cos my nan lived on a main road, I'd like to sit and I used to watch all the different colour cars and things go by and things like that. And then, few years later on, I started getting involved in watching football and stuff and I used to enjoy that. And then about my last three years at school, four years at school they just started getting a disabled football team together, in wheelchairs. And I played in that which I enjoyed. But really no there wasn't, I used to enjoy myself but there wasn't the facilities and the help to do things like there is nowadays.

Can you tell me about any sort of happy events or celebrations like birthdays or things [both talking together] like that you can remember?

I think one of my happiest memories of my birthdays or celebrations was when I think I left school and [laughs] I did not like it very much at all. But I can always remember I was so excited on the day I left, that three of my friends they sort of done up my chair and that. And I always remember that day of being such a day of freedom. But I think one of the better things I can remember is when I reached the age of... I think it must have been... let me think... about 17. My nan done me a party and I'd never had this big party like this before and a lot of my friends come and I always remember that.

You've told me a lot of things about your nan; would you say that you were closer to your nan than either your mother or your father?

Oh definitely. Definitely I mean I get on well with my mum now but we're not [doorbell] really that close... We're not really that close.

So when you were a youngster would it be your nan that you shared any worries with?

Yeah, can we stop for a sec 'cos I think...?

[Break in recording.]

Yes I was definitely closer to my nan and my grandad. They brought me up – and I say with a open heart in this and I'll still say it today – without my nan and my grandad bringing me up they way they did [door slams] I would have been a cabbage. It was only that they used to involve me as much as they could and...

Can you tell me anything about any memories you had about having pocket money and how you used to spend it?

Yep. I always remember on a Friday my mum, well, my nan and my mum used to give me my pocket money. And my delight was always going to get my Milky Bars once a week. I'd go and get me Milky Bars and I used to love going to get me Milky Bars and stuff. Once a week I'd have them and me bottle of lemonade – me raspberry lemonade. Oh yeah that was one of the highlights of my week.

I'm just going to stop a minute. Is there a problem? [Third person, 'No.']

You said to me earlier on, Melvin, that you felt that you got more education after you left school. Would you like to tell me something more about that?

Right well... [Coughs.] Excuse me. When I left school and I thought, 'Well what am I gonna do now?' Because I was about 17 and I hadn't had a lot of education at all and I used to just go home and I lived with my nan again and my nan used to say, 'Well we've got to get you involved in something. You've gotta do something in your life.' So she said, 'What do you like doing?' So I said, 'Well, you know me, I'm always interested in cars and everything else.' So I went down to a local garage down the

road and I didn't actually do any physical work but I used to sit down there and watch them mend the cars and do up the cars and I'd ask questions about things. And that's how I began to learn things better in them days to what I did at school. And then I met so many people and then my life begin to change again and I think I learnt more in the years since I left school – how to accept and how to do things – than I did at school. I mean I love the opportunities that the people who've got cerebral palsy now do today, to what they did when I was at school, if you can see what I mean?

Hmm. Did you have any attachment to any church organisation or did you go to church or were you not interested?

Yeah, I used to go to Sunday schools a lot and then I went a lot because a couple of young people I know they was my friends and they used to go. And they used to be telling me, 'Why don't you come with us?' So I went and I used to just go but I wasn't that heavily involved. And then about a year after I left school a friend of mine – he was a Scout – and he got me involved in going with the Scouts and I used to go and do a lot with the Cubs and the Scouts for quite a few years.

Can I just stop you there I want to recap, no keep it on. I want to recap and I'm not sure, I don't think I asked you this question but where exactly were you born?

Where was I born? I was born in a village about five, six miles from here, called Westoning.

Can you tell me how old your parents were when you were born?

My mum was about... I think my mum was about 29, 30 and I think my dad was about 20-odd as well.

What did your father do for a living?

My father used to drive a lorry. He used to be a fruit and vegetable salesman up in London.

What about your mother, what did she do?

My mum used to work in one of the factories on a tool lathe. She used to make special these equipments and stuff.

I'd like to just explore with you something around what type of birth issues... did your mother ever tell you or your grandma anything about your birth?

The only thing my nan told me – my mum never used to tell me anything – but the only thing my nan told me was that it was to do with oxygen what caused the problem that I've got. And the only other thing that my nan knew because my mum didn't even used to even talk to her about it, the only thing my nan knew that I got a nerve missing in the bottom of my spine and that's what caused my disability like I've got it.

Did your parents or your nanna receive any medical advice?

Well no, not really. I mean in the end we did eventually – but it was my nan again that decided – 'cos I wasn't gonna sit up very well, there was something wrong with me. Me mum kept saying, 'Oh he'll be OK.' But my nan said, 'No he won't.' She said, 'There's something not quite right with him' she said. And they got the doctor in and that's when they said that I was lucky to be alive because when I was born apparently, they said I only weighed about two pounds... or two-and-a-half pounds. And I had to go on drip feeds and everything for a few days because there was something wrong with me so...

How old do you think you were when you discovered you had cerebral palsy?

I think when I realised I had it, I must have been... about nine-and-half when they realised that something was really, really wrong.

Can you remember anything about the reaction of non-family members like neighbours or family friends to you?

I can always remember what some of the neighbours said. They said, 'Oh well, he's gonna be a cabbage.' And my nan said, 'No he won't be a cabbage.' She said, 'He'll be all right.' She said, 'you people've just gotta accept him.' And I think even up to this day that my grandma could accept it but my mum still to this day – though she accepts it more now – still can't really accept that I'm disabled, I'm a human being and I've got my life d'you know what I mean?

Mmhmm. What memories do you have of being outside or playing outside in gardens or [both talking together] local parks?

That's where some of my nice memories come in because I was the only one, so I ain't got no brothers and sisters. And my nan, she used to sit me outside and some of the children – they was very innocent, they didn't mean anything by it – and they always used to come and talk to me but I always remember one of the memories. I always remember, I went over the park, over the 'rec' as we called it and one boy said 'Hmm he shouldn't be here' and my mate Dave, he said, 'Pardon, why shouldn't be here?' So he said, 'Cos' he said 'he can't do anything, he shouldn't be here.' So my mate turned round – this my Dave my mate – he said, 'Don't talk to him like that' he said 'he's got as much right to be here as you have' he said. And I never ever forgot that, that's one of my first memories I remember, really made me realise that I was different to oth...

Did you ever go round to a friend's house?

In later times I did. I used to go round to a couple of my friends; they'd have me round their house. They used to accept me in and go round there and that become a part of my family.

Did you ever go around in a group of lads?

There was always about three of us at one stage, we'd go together but there wasn't that many. It'd be sort of three pals that really sort of accepted me and the rest of them would sort of go along with us if they thought they was missing something.

What about going out to the shops, have you got any memories of that?

I remember the first time I went in a shop with one of my young friends and somebody said, 'Urgh, what's he come in the shop for? He won't know anything about it.' And again one of my friends said, 'He's got as much right to come in the shop as me.' But I always knew it was strange to do things.

Have you got any early memories of travel or holidays?

Yeah. I think one of my first memories I've ever had of travel is the first time I went to seaside on the bus because I could never walk so I had to be carried up the steps. And my grandad carried me up the steps and this bus driver said, 'Oh we ain't gonna do this are we?' And my grandad said, 'Yeah' he said, 'he's all right, I'm gonna bring him on the bus.' He said, 'I'll do it,' he said, 'there's no problem with that.' And I can always remember the horrified look of this bus driver's face because I've, come on the bus.

Did you ever move house when you lived with your grandparents at all?

I moved from my nan's – when my nan died – to my mum's and I lived there for another 10 I s'pose.

How old would you be when you moved from your nan's?

I must have been... let me see 16, 17. I must have been about 18-and-'alf when I moved from my nan's.

Eight-and- a-half?

Eighteen.

Eighteen-and-a-half? So you were quite grown up then?

But I can remember it as if it's tomorrow because it was a different life once I went and lived with my mum.

What better or worse?

Worse in a way for me.

Would you like to tell us something about that?

Yeah... I think the reason why it was worse for me. I got on OK with my mum and my dad to an extent but they never accepted me the way my grandparents accepted me.

Do you think in a way they were pr'aps ashamed of you?

I think in many, many ways yeah or I didn't come up to their expectations, I don't think.

Tell me something about when a woman has a baby she expects it to be perfect and it's quite a shock to mothers when they have a baby that's disabled. Would you think that was the same for your mother would you like to...?

I think so, I mean even to this day I mean my friends who've I got and I think the world of – I've got two or three real special pals – they're my family now. They're my friends and they're much, much closer to me even now to what my mum is. I mean I care for my mum – I get on with my mum – but there isn't the bond there what you think there should be.

Are your friends disabled friends or non-disabled?

I've got a couple of disabled friends but most of my friends are non-disabled friends really.

Were you allowed to go your nanna's funeral?

No.

Would you like to tell me something about that?

My mum said, 'No you can't.' She said, 'You can't get up the road to your nan's funeral 'cos' she said, 'we can't take you.'

Did that upset you?

And I thought, 'Well OK.' I was really cross. I was really, really cross at that. And I let that go but I was so angry that I let hem go and I can remember it as if it's today. I let hem go and get on with what they gotta do and I let my mum go off to the funeral and I remember to this day that I let hem go and I don't know how I done it. I don't to this day; I don't know how I dare do it 'cos I don't even think that I dare do it today

but I was so angry. I had an old chair like a Dalek chair and I got it out the front door of my mum's place – after a struggle – and I went up to the cemetery where my nan was buried. And they didn't know I was going and I took myself up there. And the minister or the vicar was there and I hid behind this tree and my mum walked down

the path. And my grandad was upset because my mum wouldn't... 'cos they was really close nan and grandad. He was very upset when nan died, he was very upset and he walked down the path, and I don't know what made him look over to where I was at all to this day and he said, 'Who's that behind that tree?' I heard him say and my mum looked and she said, 'I don't know.' So I let her go by, I let her walk past and I said, 'It's all right,' I said, 'it's me.' And... to cut a very long story short, well bit shorter, I got quite an ear bashing when I got home.

Were you allowed to go to see your grandma's grave?

Yeah in the end I did.

Not at the time of the funeral though?

No but in the end, I did go once they'd gone 'cos I went up to the grave myself and done it you know.

Mmm, that's very sad... Let me see where I'm up to... Did you have any pets as a youngster?

Yeah my first pet I ever had when I was a youngster I had a rabbit 'cos I used to like rabbits and then I had a dog and I had loads of dogs over the years. And cats and dogs were my favourite and they still are... and yet that used to keep me company a lot of the time.

I'm going to move on a bit now to after you left school Melvin.

Right.

You've told me a bit about what you did after school. Did you ever get any opportunity to study once you'd left school?

Not really, I didn't because even to this day I do things but I need a lot of help to do them. So at that time... I've learnt more since I've come to live in Leonard Cheshire here because there was more opportunity to help me do things here to what there was at school and that.

When you were growing up did you have any opportunity to meet members of the opposite sex?

Again I was always very lucky I had friends – girls and boys – that used to be my mates and I used to meet some of them but I didn't really have a lot of opportunity I just used to make the most of when they come to see me I'd do it then.

Who would you say had the greatest influence on you?

What as a friend?

No... A grown-up person in your life.

A grown-up person in my life?

Mmm... Looking back

Looking back... Well there's a lot of people but looking back really... and again I know I keep 'arping over the same thing but again, I gotta say it was my nan and my grandad.

Can you tell me something about the kind of house you lived in with your nan and your grandad?

Yeah it was a big old, rambling three-, four-bedroomed house and it had a cellar and a big garden and I used to go down into the garden and that kind of thing.

Stop it [break in recording].

Talk now about more about your adult years OK?

Right

When you finished education. You've told me already that you weren't able to go to work; do you want to tell me something about your voluntary work?

Yeah well really, about that, you say my years after I left school. Again I used to live with my nan and then I got a bit fed up of being in the house all the time. So social services decided that they'd try and help me get to a day centre. And after some long discussions and that I needed help to go to the toilet and that because I couldn't manage that on my own and in those days at the beginning there wasn't many places around Bedfordshire that'd really take somebody in a wheelchair that needed help to go the toilet and that, to go to a day centre. So, after some searching around they found one centre that'd be willing to have me and it was a day centre for the elderly and handicapped in Leighton Buzzard and I went there. And there was a lady called Heather she was there when I first went and she helped me and I started going once a week, twice a week, eventually I went three times a week. She helped me for about five, six months – no about four months to be honest – four months she helped me and she had to leave to have a baby. So they said at first, 'Oh, well Heather's leaving, so we don't know whether you'll be able to come or not, you know.' But they said, 'You can keep coming for now.' Anyway, they interviewed a lot of people for the centre's job and they got this guy called Peter. He took the job over – centre manager – and he was very happy to keep me there and I went there for a number of years. There wasn't again much I could do because my hands and that were so bad I couldn't do craft work and all that kind of thing and again my reading used to let me down. So I just used to go on and sit and play dominoes and that. And then one day they were so short in the office and Peter was always encouraging me to do something, so he said to me one day, he said, 'You come in the office with me for an hour.' So I thought, 'Oh I

can't do nothing in there. I can't read and things like... I wouldn't be able to help. I thought, 'That'll be a change, I'll sit and watch what he has to do in the office.' So...

[End of Track 1

Tape 1 Side B [Track 2]

I'm interested to hear about your office work in the day centre but just so that we get it into context, how old would you've been then Melvin?

When I left to go the centre I was about 17-and-a, 16-and-'alf rather.

So tell me about your experience in the office then.

The experience in the office was, 'Well I never done this.' But he said, 'Don't worry' he said, 'it's people who you know.' And he said, 'It's only people who come and pick you up on transport and that' he said. 'You know the drivers; just pick it up and say, "Can I help you?"' He said, 'I'll put the phone so you can get at it. And I'm gonna do the bookwork and then you answer the phone and if it's anything they wanna know I'm here, I'll take it over and I'll do it.' So I done it for him this particular day, 'cos he'd got a lot to do... and transport and a lot of paperwork to do and I done it and he says, 'Right that's fine you done well today.' He said, 'You come in tomorrow.' So I said, 'Yeah.' He says, 'Like you usually do.' So he didn't say anymore, so next day comes, I come in the front door of the centre and he says 'Come on then, in the office.' And I said, 'Pardon?' 'Come on' he says 'you're coming in the office with me again today; I've got a lot of paperwork to do.' So I sat in there and I took the messages on the phone for him and that, I done that for another day and then he says, 'Right,' he said, 'you done so well' he says 'you can always answer the phone for me.' So I done that for about a week and they got radio-controlled ambulances you know, the old ambulances. And that he say to me 'Right,' he said, 'you can help with the radios of the vehicles' he said, 'cos it's only the drivers you know.' He said, 'You can help me' he said, 'cos I got a lot of bookwork.' I have to keep giving them message and things and he said, 'If I tell you what to tell them you can tell them' he said. 'And you can do it.' So I started and in the end I was doing this every day for ooh 10, 12 years and I learnt a lot about vehicles, specialised transport and all that. And in the end I was running the control unit in the centre, about eight to nine vehicles for the council, I didn't get no money at all for it but I

How did it make you feel?

Oh I felt absolutely brilliant. I felt absolutely smashing to be able to say I've got something to do. And then the biggest memory I always remember was one winter's evening, near Christmas. They got a lot of elderly people that they gotta go out to them on Christmas day and deliver their dinners but they needed a person in the control office. So they said to Pete, 'Well will you do the control office for Christmas day?' He said, 'I can't but' he said 'I bet I know somebody who will if we'll go and pick him up.' He said, 'I bet if I ask Melvin if we can go and pick him up' he said 'he'll do it I'll bet.' He said, 'If we pick him up I bet he'll come in willingly and he'll do it for us.' And I went in and I done that for three Christmases running and I met so many friends and learnt so much about life and people that way, that's where I say my life changed then.

So I want to move on now, if I've done my sums right if you were doing that for 11 years it would be just before you were 30, so let's move on. How old were you when you came to live in this bungalow where you are now at the Cheshire home?

Well in the bungalow... I been here nine years but in the Cheshire home I s'pose I must have been 31 or 30 when I come in here.

And is that in the same complex as this or somewhere else?

No it was actually in the home, exactly the same place but it was in one room in the home.

Whose suggestion was it for you to move out of there then?

Well, it wasn't a suggestion, at the time there was a notice up on the board in the home, anybody interested in doing semi-independent living to live in the bungalow

that they'd developed please put their name down. And I thought, 'Oh I'm not gonna do that' and nobody seem to put their name down so I thought, 'That's weird, they're gonna have a bungalow for themselves and nobody wants to put their name down. And I wanted to do it but I thought I was too severe to do it. So I asked then the head of care who was Judy Pine [ph] if I could put my name down, so she said, 'Yeah' she says, 'you can put your name down.' She says, 'Come back and see me tomorrow' she said 'and I'll tell you what we're going to do.'

Let me just stop you there. I'd like to talk to you before we go on to that; tell me something about the daily routine when you were actually in the home itself.

Oh right, my daily routine.

Time you got up, things like that, what sort of...

Right. Time we start getting up is seven o'clock in the morning, quarter to seven, seven o'clock in the morning we get up.

Was that your choice?

We didn't get the choices then like we do now. We still don't get too many choices but we get many more choices than what we used to then. But when I first come here it was the time we used to get up and that was it but I didn't used to mind because I'm one of them I always like getting up and about, so that never used to bother me really. I was always very pleased to get up and about but...

Did you get any choice about the type of food you ate?

Not really in the first few years. But now we do but in the first five or six years there used to just be a menu and you'd do that but now for the last five or six years we've had menus and choices but...

I'm really interested to hear about the early years when you were actually in the Cheshire home. Can you tell me something about privacy and whether you had any privacy?

Privacy... not really and even to this day. I mean I get more privacy here but even to this day because it's joined on to the home, privacy even now isn't like it should be.

Can you explain that a bit to me?

Yeah I think the reason privacy is not... Because I think they always think, well because you live somewhere they've got a right to come in and do what they've gotta do when they want to do it.

When you lived in the home, obviously I should... was it men and women together?

Yeah there...

Did any of the residents have opportunities to get married and be with their partners?

Well when I first come here one of them had just got, well they'd been married a few years but because they were married they let hem stay here. But nowadays and even then there was only one couple I've ever known do that.

So how did people living in the home have opportunity to make relationships with the opposite sex?

Well again, I don't think they did really I mean they used to go out and that but I think even now you either gotta go out or you just gotta shut... I think even to this day there's not the opportunities there should be.

And that's interesting. Well could you explain it a bit more to me?

I s'pose there is more opportunity than what there was then but I somehow think that when you come to live in a residential place – I 'spose I sound a bit regimental but I don't mean to – I think they forget about the personal side of life I really do.

Do the staff knock on your door and wait to be asked to come in?

A lot of hem do, a lot of them feel that they can come in when they want to but a lot of hem now do knock on your doors but that's only improved the last few years.

OK. So we've talked about while you were in the residential home side; let's talk about... have your daily routines changed since you've come to live in this shared accommodation?

Yep. Again it's changed, again it's like a seesaw my life but it's always had happy, happy memories. Again it was smashing when I first come to live in this bungalow because until finances changed the situation I used to have what they call 'care at home services' come in from outside and get us up in the mornings, help us with our baths and showers or toileting or whatever, help us with our breakfast and all that kind of thing, in them days but...

How long ago is that?

That's coming up for four years, three-and-'alf years since they changed it.

And what happens now then?

And what happens now is that I'm here and I am looked after yes but I'm looked after by the same staff that look after the residents in the home. So that means that they have to share the staff from the home to come over to us over here and....

What time do they come over to get you up then?

It's going back to what it was years ago; it's about seven, quarter past seven in the morning and that

So what happens at mealtimes?

Well mealtimes, unless I do my own which I do quite a bit in my microwave or whatever, I either gotta go over there at half 12 to have my dinner or six o'clock to have my tea or half past nine to have my breakfast.

So you're not getting individual care here then?

No.

So would you say that this is any way like independent living or have you just swapped the building for another building?

I think in a way it's better for me because I've got my own front door. I've got a lot of friends, so I can enjoy my life better over in the bungalow here to what I could but I'm really only swapped to another building in another way. And though I've got a bit more privacy over here I – quite a bit more privacy over here really – to what I would have over there.

What happens to people that live in these bungalows that haven't got the friends that you've got?

Well there's only one bungalow like this and anyway they either have to rely on the staff to come and do them and they have to go and do their, have their meals over there or my friend has to go and have his meals over there in the home or he has to come in here and do his own which he doesn't wish to do.

What about opportunities to get out if you've got no friends?

They've got activities department, which they do get out to places like the pictures and shopping once a month, so they can get out but it can be difficult at times if you need somebody with you.

Is it always a group activity?

A lot of the time there is some one-to-ones but most of them it's couple or three at a time.

OK. How do you think that attitudes to disabled people have changed from your childhood to now?

I think attitudes are definitely changed and people have changed but I feel that they've still got a long way to go. But attitudes have changed in lots of ways but you always will, I feel you'll always get somebody who don't believe you can talk up for yourself.

Have you been able to achieve any personal transport mobility for yourself?

Yeah I'm very lucky 'cos I've got my own car and I've got a couple of friends or three friends that'll drive my car for me about when I wanna go out weekends or nights in the week or days in the week if I really wanna go somewhere. So I'm very lucky that way.

Do you get any opportunity to go to the cinema or the theatre or musical events?

Yeah I mean again, I'm lucky I can go to the pictures and things myself if I want to and I do when I want to. I go over to a place called The Stables in Wavendon and they have different concerts on over there, that's quite nice.

Do you ever have the opportunity to go on holiday from here?

Yep. We have the opportunities and I've done it a few times. We do what they call homes exchanges and that, so we just change from one home to the other.

Do you think that's satisfactory?

It's nice for a break but to me it's not a holiday. It is nice for a break but it's not an holiday. Again I think going away on a holiday when you're disabled or severely disabled can be quite a cost to a person I think.

You don't have to answer this question Melvin if you don't want to but what access do you have to personal spending power?

That's one thing I don't mind answering on. I mean one thing I can say for this place, if we're able and we're bright enough, even with help, to look after our finances we can say what we want to spend and all that ourselves but...

So can you, for example, have your own bank account and draw money out yourself?

Oh yes.

Right

Yes, yeah

For people pr'aps that are... what I need to know about yourself really, more than other people but do you find that you have an added amount of money to spend on the things that you want to spend it on?

I have to be very careful because it costs so much to live in places like this, so I have to be very careful how I spend my money because if I don't then I could have a

problem but I manage 'cos I've been used to managing for years, I manage my money quite well.

So, you're not doled out spending money each week then?

No.

No.

No, we get allowed £13-odd out of our it could be 15 now in fact, I think it is £15 now out of our actual weekly disability. We're allowed that because the local government pay for me to be in here.

What about your mobility allowance where does that go to?

That'll help run my car and my clothes and stuff for that.

So you're allowed to keep that?

Yes, yeah

OK. Right now we're going to move on, are you sure you're all right?

Yeah

Not tired?

No you're fine.

'Cos I can come again if you're getting tired. OK, we're going to move on now to talk about relationships outside of your family. You've told me a little bit about your

friends and that you've got three very good friends. What especially significant relationships would you like to describe to me?

In what way do you mean?

Well people that have meant a lot to you, not your nanna but your in your adult life

Oh no, well right no, not my nan but...

Mmm

I mean I've got a load of friends that are good pals, they are good friends but I'm very lucky as I said that I've got two, possibly three mates that are like my brother, like my sister. They're not but they are like that and really to me they help me with my disability they help me to accept my disability

Are these people married people or?

Yeah. One of my mates isn't but the ones that I see more of they are married.

Would you like to tell me something about your views on sexuality and relationships?

Yeah I mean, again, I think that's a very personal thing. I mean, it's never bothered me and it doesn't bother me now. I s'pose it's an old saying, 'what you've never had, you never miss'. But I always think if something come along and it happened it'd happen but myself personally it doesn't bother me really.

So have you ever thought about what it would have been like to be a parent?

Oh I've often wished that I could be a parent. I could get married, pr'aps, have a wife or something. But again I've always wanted to be a parent but I'll be honest with you

I always think, well with my disability I don't feel that I can personally bring up the kids to help them like I should or be able to support them like I should, so I feel...

What about other disabled people – women – that you might have met in this home?

Again I've met some but again I don't know, I think it's probably me but I just feel that it doesn't bother me. To me life's a laugh and a joke. I mean if somebody come along, even at this late stage of life, then again my life might change but I've never had that side of life to worry about really.

OK, so we'll move on now to talk about contact with other disabled people. How would you describe your contact with other disabled people that you've met here? Or anywhere?

Right, well me own personal experience is I've got a couple of real good disabled mates who I get on all right with. But I always find myself, most disabled people – not all of them and no fault of theirs I s'pose, it's probably me again – but I always find that a lot of disabled people have got their own ways of dealing with things and I don't know why but I always find other disabled people quite difficult to talk to.

Have you ever had anything to do with organisations of disabled people or... like Scope membership or something like that?

I used to go to a Phab club for a few years... and I met a few friends there, then it folded up, so I didn't go. But I'm not really – apart from saying, 'How are you?' and talking to the people here – I've not really had that much to do with other disabled people I always say, 'hello' and 'how are you?' and all that stuff but I've not really had that much to do with them. I've always sort of done me own life really.

Can you tell me whether you've ever heard of an organisation called British Council of Disabled People?

I've heard about it yeah.

What?

I don't know much about it.

OK that's fine. Are we all right Lisa? [Third person, 'Yeah.'] Have you ever heard of, for example, the 'social model of disability'?

Yes. Yeah.

You have. Do you think it's a useful model?

I think so; if it's adhered to properly it's a good thing.

Do you think that if the staff here adhered to it you'd have a better life?

I think so, in a lot of ways but there again I think you'll get 'some will, some won't'.

What equipment or aids have been the most useful for you?

Well the things that I've found since I've lived in here all these years, is the electric hoist to put me in and out of bed.

Mhmm

That's saved a lot of hassle and it's been more comfortable and things like that to move around.

And what about your wheelchair?

And my electric wheelchair has been my life-saver really.

How old were you when you first had it?

When I first had electric wheelchair I must have been about 13, 14, I s'pose

What was that an electric one?

No.

No.

When the first electric one, I must have been about 16, 17...

Can you tell me, did you have any sort of celebration for being 21 or 40 or...?

Yeah I had a 40th birthday [laughs] and that was quite a nice celebration but I had a big 50th birthday and that I can remember a lot about. Some good friends I know... I organised it all myself. And a couple of my mates done the disco and that for me and that was nice to... That's the first time I've ever had a big celebration like that.

Have you got any thoughts about being retired and your retirement? When you get to 60 or 65 for you actually?

Yeah, I don't know 'cos in a funny sort of way I'm not retired but in a funny sort of way I feel I am now sometimes.

So can you see any changes?

I think the only changes I'm gonna be aware of is if I can keep smiling and keep my sense of 'umour because I think if I don't then I'll feel that'll be me, d'you know what I mean?

Can you tell me about some of your aspirations for the future what you'd like to see changing in your life?

Yep. I think the biggest thing I would like if possible would be to own my own bungalow and to move out into the community.

[Both start to speak at once.]

Do you see that as being an option something that will happen?

Well I hope to think it will but I'm always an optimist, so I say it's gonna happen.

How often do you actually get to see your social worker?

Usually about once, twice a year.

Do you think that's enough for her to chivvy the housing schemes up and make [both talking together] sure you're on the list?

I chivvy them up as well and they know I'm getting annoyed about it, so...

How long is it since you made it known to them that you want move out of here?

Over two years now.

And do you think you're any further on?

A bit but not a lot, no.

Hopefully you will get your own home Melvin and you'll be entitled to receiving direct payments. How do you think because you've never been employed yourself, you'll feel about employing staff of your own?

I think I'll be a bit concerned but because I've had quite a bit of experience of meeting people and I know a lot of people that know me and I'm quite outgoing – I like to think I am outgoing, friendly person – I'm just 'oping that I can cope with it.

[End of Track 2]

Tape 2 Side A [Track 3]

No transcript available