



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

Anne Pridmore  
Interviewed by Anne Austin

British Library ref. C1134/13/01-04

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## Interview Summary Sheet

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|-----------------------------------|---|--|-----------------|
| <b>Ref no:</b>                    | C1134/13/01-04  | <b>Digitised from cassette originals</b> |                 |
| <b>Collection title:</b>          | Speaking for Ourselves: An Oral History of People With Cerebral Palsy   |  |                 |
| <b>Interviewee's surname:</b>     | Pridmore  | <b>Title:</b>                            |                 |
| <b>Interviewee's forename:</b>    | Anne  | <b>Sex:</b>                              | Female          |
| <b>Occupation:</b>                |   | <b>Date and place of birth:</b>          | 1939, Stockport |
| <b>Date(s) of recording:</b>      | 8 <sup>th</sup> July 2005, 15 <sup>th</sup> July 2005, 29 <sup>th</sup> July 2005, 30 <sup>th</sup> August 2005 |  |                 |
| <b>Location of interview:</b>     | Interviewee's home, Market Harborough   |  |                 |
| <b>Name of interviewer:</b>       | Anne Austin   |  |                 |
| <b>Type of recorder:</b>          | Marantz CP430   |  |                 |
| <b>Recording format :</b>         | D60 Cassettes   | <b>Number of cassettes:</b>              | 4               |
| <b>Digitised as:</b>              | 8 WAV files (16 bit 44.1kHz 2-channel, 1411kbps)  | <b>Mono or stereo:</b>                   | stereo          |
| <b>Total Duration: (HH:MM:SS)</b> |   |  |                 |
| <b>Additional material:</b>       |   |  |                 |
| <b>Copyright/Clearance:</b>       | Open. © The British Library Board and Scope   |  |                 |
| <b>Interviewer's comments:</b>    |   |  |                 |

**Tape 1 Side A [Track 1]**

*[Whispering, inaudible.] OK. I'm interviewing Anne Pridmore in her house in Market Harborough, and today is Friday 8<sup>th</sup> July, and my name's Anne Austin. So can you just tell me a bit about where you were born and when you were born?*

Yes, I was born in 1939 in Stockport, in Stepping Hill Hospital. My mother's first child, I believe from what my mother said, a very difficult birth – I was a breach baby and my mother was in labour for about two days.

*And has she told you any more about when she was told that you had cerebral palsy, or anything about the early stories?*

My mother didn't tell me a lot about how she felt about havin' a child with an impairment, but I know that she did what she thought was the best for me, by taking me to the professional medics who I had lots of different orthopaedic interventions which, personally, I think did me more harm than good, but I realise that, you know, she was doin' it for what she thought was best and like most people, [rustling sound] we trust the professionals. I do remember one particular incidence, I don't know how old I was, but findin' a letter where she'd written to some professor of brain surgery, who thought 'e could do some sort of brain operation to alter the way I was. But I'm really pleased that she didn't go down that road. And I know that she did a lot of physiotherapy with me, which I think did do me a lot of good.

*And what are your first memories of life with the medics?*

I think one of my first memories of it was: up to bein' five, my mother 'ad taught me to walk across the room to 'er, and then the professionals decided that I needed to go into an orthopaedic hospital. And I can remember the ambulance men comin' and sayin' this basically. Cos this was just after the war and we were very rationed, I remember I was eatin' this salmon sandwich, and I remember sayin', 'I'm not goin' till I've ate my salmon sandwich'. And I do remember that particular visit to the

hospital, and that was one visit that I was actually in hospital then, possibly for about 18 months, and when I went in I could walk, when I came out I couldn't even sit up in bed. And the reason that my parents brought me out was the fact that they went to visit me one day and I'd got my legs swingin' over the side of the bed, with two pools on the floor, and they'd put my legs into plaster of Paris splints without any waddin', and basically I've still got two holes in my heels to this day from what they did.

*Can you remember life in the hospital if you were there for - ?*

I can remember it was nothin' like it is nowadays, and that we had visitn' once a month, and if anybody got any sort of infectious illness, be it a bad cold, they would stop it. No food or drink was allowed into the hospital, and I was very keen on my cup of tea (cos I've always liked strong tea) and one particular occasion my father brought me a flask of tea in, and when they'd gone home – I mean it sounds so far-fetched this, but it's true – they blindfolded me, and took me into what they called 'the physiotherapy room' and left me there, because I'd gone against the orders of the what, you know, their regime was you couldn't have any food taken in. And it was like a life of fear. And I remember, I used to have a problem wettin' the bed, and they would take me out of the children's ward and put me into the babies' ward and tie me into a cot with restrainers, because I'd wet the bed. There was a whole, really bad feelin' around anything to do with the toilet, because you 'ad to go when the bedpans came round, and on one occasion, I remember myself and one of the other people in there bein' so terrified that we found ourselves eatin' our faeces, because we'd messed the bed, and we were absolutely terrified of what the repercussions would be. I can't eat things like Weetabix because I always hated it, and I'd be sick and they'd still make you eat it. And issues around that, which was a dreadful time.

*It sounds a very harsh regime.*

Mm.

*Do you remember what your feelings were? You talked about fear, at the time.*

Just a feelin' of never bein' able to get out of there, basically. I mean I did go and visit the place a couple o' years ago to see what it was like, and it's been actually turned into a residential home for disabled people, and to be honest with you [laughing] it doesn't look a lot better now.

*So it still exists?*

Mm, and the pillar box where I used to send the letters home, was still there: it wasn't operational, but it was actually still the same pillar box.

*And you were about, what age was this?*

I was in there from bein' five to six and a half, and then I went in again when I was 13.

*The same hospital?*

The same hospital. And of course I absolutely dreaded it, and whilst it was better it still wasn't that good.

*And, I mean, was the idea that you would have therapy and... I mean, were you havin' a lot of operations?*

I think the idea was to straighten me legs, so they put my legs in these plaster of Paris splints, but of course as soon as they took them out, they went back to how they were. When I was nine, I started havin' my [rustling sound] orthopaedic operations, and I had my first orthopaedic operation when I was nine, to lengthen the tendons behind my knees and the back of my ankles, but I was actually [dog barking in background] sedated too much because anaesthetics weren't like they are now. And I remember my mum comin' in to visit me and them sayin' to 'er (or she told me this) that I hadn't come round, but not to worry because sometimes they don't. And so I 'ad those two

operations, I had 49 stitches in each leg behind me knee when I was nine, then when I was 13 I went and had the same things done again, and then I had nine stitches. And whilst it did lengthen the tendons in my leg, and I had callipers on, there wasn't the muscle power to support keepin' my legs straight, so as soon as the callipers came off, I was still walkin' with my legs bent.

*So all this regime didn't have any good effect, [talking together] as far as you can tell?*

Well, I don't think it did because of some of the work I've done in the past – I was a residential home visitor to four men who lived in a Mencap home, all of whom had cerebral palsy like myself, and I found it interestin' that, yes they'd had a worse time than me because they'd been dumped in a psychiatric ward till they were in their late fifties and sixties, but none of them had got arthritis because none of them had been made to walk, and I think that's quite interestin'.

*I mean what do you feel about, you know, the ideas that were... And presumably they were doing it for the best, they were wanting you to be as...*

[Talking together] Mm.

*... 'normal' as possible? I mean, think, looking back, what are your feelings about that?*

Well, of course as I've got older and joined the work that I'm committed to, I personally feel that you shouldn't be tryin' to change the individual, you know? We should be changin' society, and the structures of society. I think there's a lot of medicals and professional elitism, they get a lot of elitism by doin' all this orthopaedic work, and I don't see any research done on people with cerebral palsy to see what the lastin' effect of all this surgery is. I don't think it's that good myself.

*And what about your mother, particularly? I mean, how does she talk, or how did she talk later, about the fact that you were away from home and being in hospital and so on? Do you remember anything she said about how she felt about it?*

Funnily enough, I don't think we ever really had the conversation, which I suppose in itself is quite interesting really, [interviewer starts to say something]. Although I really believe that she did it because she thought she was doin' the best for me.

*And your father? Did he have - ?*

Well my father was sort of... Because he went to war the year I was born, we didn't 'ave a very close relationship. I can remember 'im visitin' – I think I must have been about two – and I can remember 'im pickin' me up and seein' 'im in 'is RAF uniform, and me lookin' over the shoulder through a mirror. [Sound of engine noise in background.] I think I very much misjudged my father, which I understood better as an adult.

You feel he didn't have as much say?

I don't think he had any say in things really, and that was the sort of marriage they had: she was obviously the stronger one. My father went into insurance after the war, and he was out a lot in the day and sometimes in the evenin'. And my granny lived with us till I was 16, and I really didn't understand that my mother was quite lucky that my granny did loads of the work, and my father did as well, and that 'e didn't really 'ave a lot of say in things. But I didn't understand that until I was older and I got married, lookin' back on it.

*Did you remember activities with him? Playing, reading, with your father?*

No. I can remember doin' things with me mother,

*Yes.*

but I don't remember doin' anything really with my father. I don't, no.

*Do you feel he was sort of a remote figure?*

Yes, but not because he really wanted to be.

*And your mother? What kind of relationship did you have with her?*

I had a very close relationship with me mother until I told her I was gettin' married, and then it went badly wrong. [Rustling sound.] I met my ex-husband at a college for disabled people when I was 21, and she was very welcomin' to him, even when we got engaged, and was proud to tell people. But I think she never realised that marriage would be on the cards, and once we named the day, everything changed. And in fact we spent the two weeks before my weddin' sendin' notes to each other. I mean she did come with me: on the surface it was quite unnoticeable because she came with me to help me choose the dress and all that type of thing, made my sister the bridesmaid's dress and all that, but she wasn't happy with me becomin' independent.

*How did that feel for you? How was that?*

I think at the time I was so taken up with the fact that I was gettin' married, I don't really think it registered. I mean, in many other ways she allowed me my independence because, I mean, she sought very hard for me to go to what we used to call 'mainstream school' in those days. And when I was five, [dog barks] she 'ad 10 trips to school in order that I could go to the mainstream school, cos she'd take me to school, then come back, then she had to go at the tea break, and then at lunchtime and back, tea break in the afternoon, and pick me up, because they wouldn't allow me to be in the playground [rustling in background] on my own because of course there was no support as these days. So she taught me a lot about independence and made sure that I had as 'normal' a childhood in that respect, and I went to youth clubs and things like that. When I got to be 10 and changed schools, that didn't happen. I used to go,

and then one of the other children I'd go out to the playground with, and things like that. I can't quite remember how [it] worked but she didn't have to go. So in one respect she did teach me that type of independence, and I was at work [dog barks] when I was 14, I was in full-time work from bein' 14 for 25 years which, considerin' my impairment, was quite a feat. They sent me to a private business school to learn shorthand typin' and book keepin', and I 'ad to do the English and Maths because I left school early, [dog barking] and everybody was told that they'd get them a job at the end of the [someone says, 'Sh, be quiet.'] 12 months, but in fact they wouldn't promise me that because I was disabled. It was a mainstream college, but in the beginning... [laughing] I'm probably ramblin' on [laughing] a bit now but...

*It's alright.*

In the beginnin' I used to tell them [dog barking and someone talking to it off-mic] when I wrote for jobs that I was disabled, and then I found that if I did that, I wouldn't get anywhere. So then I used to not tell them, and turn up and watch the horror on their faces. But I finally got a job through doin' that [sound of door banging] when I was 16.

*That shows a lot of independence.*

Mm.

*And your mother encouraged you at that stage?*

She did, [dog barking] she encouraged me all the way. Can you just turn it off a minute? I'll just see if I can stop that. [Break in recording.] I'm glad that me mother taught me this independence, but I've always felt a bit like the philosopher that tried to get to the top of the mountain and kept rollin' back (I can't just remember 'is name at the minute), because I always, until my husband left me, I didn't really come out as a disabled person. I didn't realise that I was disabled because I've mixed in a non-disabled [sound of knocking] world. I'd gone to mainstream school, at 15, 16, I took a

job, and I worked till I was in my forties, so it didn't really hit me. But at the same time, I felt that I never was able to reach my potential because she'd given me this sense of ambition which I was never able to fulfil, because most of the jobs I had were very mundane office jobs, and I've always felt I could 'ave done a lot better.

*And what would you have wanted to do? I mean, you have ambitions: what would, you know, at that stage perhaps, to reach your potential, what would have that have meant?*

Well, I don't think I had a very good education. I took a degree when I was in my forties, but by the time my husband left me when I was 44, and by the time I'd got my care package sorted out, it really wasn't worth lookin' at a career, because like many disabled people it's very frightenin' to come off the benefit system. And there weren't the incentives there are now, if you like, although I don't think they're really good but... So I often say, if he'd have left me 10 years earlier, what I would have liked to have been would have been the chief executive for British Council of Disabled People, [both laugh]. But it was all a bit too late for me by the time that, you know, happened. Or, if I hadn't become political, I've always fancied myself either as a teacher or a journalist, cos I quite like writing.

*[Rustling noise.] Can we go back a bit, because you've told me a lot, and I was wondering if we could go back a bit p'raps to childhood again? You've spoken about your mum and your dad, and your granny...*

[Talking together.] Mm.

*What part did she play in your life?*

I think me granny played a really big part in my life up to bein' 16 when she died, because she always lived with us. My mum and dad lived in a house up to the time the war started, which they were given the offer of purchasin' for £350, but that was just far too risky for me dad, and he was goin' off to war, so me mum decided to go and

live with my granny. And my granny kept a shop in Stockport, a sweetshop, and obviously it was durin' the war, and I remember that when the sirens went off, we all 'ad to go in the cellar. We'd take hot water bottles and like a picnic and go off into the cellar, and I can remember some parts of the war where somebody across the road – a bomb had landed on the house. And I remember goin' out that next day, and seein' the shop front was shattered, but we were alright, but just our shop window, and [engine noise in background] seein' this house where you could just see the upstairs was like a shell, and I always remember somebody sayin', 'See that bed? They were lyin' in that bed at the time'. [Interviewer laughs.] Now whether that was true or not, or just a bit of a childish memory, I don't know. And I can remember my granny havin' to count up the ration coupons, and she'd put them all into little piles of the different denominations, and then I can remember blowin' on them and scatterin' them all. [Interviewer laughs.] I can also remember sittin' in the toffee shop, and customers'd come in, and if it wasn't one of their favourite customers, or their best customers, I would say, 'No cigarettes today for you,' and give the whole game away, and I do remember that. [Interviewer laughs.] Me granny, yes, she did play a big part. She was very supportive to me mother with meself, and as I say, she lived with us till I was 16. I think she took quite a share of the housework and things like that. Mm.

*And brothers and sisters, do you [talking together] have - ?*

Right, my mother had another baby when I was about 10, with cerebral palsy, the same but much worse – it had hydrocephalus, died when she was four days old. And then my mother decided they'd adopt a child, so 12 months later [banging sound in distance] they adopted my sister, Catherine. But I've always felt that they adopted 'er for totally the wrong reasons. One was to replace the child they'd lost, secondly I think they felt that somebody to look after me in my old age, and thirdly to 'ave a perfect baby. And, while she was a youngster it worked OK, but as she got into 'er teens, things went really badly wrong. My mum and dad used to do quite a lot of ramblin', and it got to a stage where they weren't able to leave me in the house with her, because she wouldn't do anythin' for me. And... I think I'd better tell you a bit about what happened later on, [laughing] cos it's forward on in the story. So there was

Catherine who was 11 years younger than meself, and although, yes she was adopted – we had her when she was 10 days old – we never looked on 'er as any different. But I think she was quite a culture shock to my parents because a lot of the things they'd been able to – I didn't want to have parties and things like that and go out as much as she did. I probably wanted to but I knew it was impossible. I think that they found it all a bit difficult with her. I found my teenage years especially difficult, I'd got loads and loads of friends until boys came on the scene, and once my friends got boyfriends then they didn't really want to know me, so I found that a very sad time.

*Yes, that must have been very painful. And how did you feel about your adopted sister? Did you get on with her?*

I got on with 'er up to till she got to be about 13. But when she was 13 I left home then to be married, so...

*You never played with her? Well she was a bit young.*

I was allowed to feed 'er and things like that, you know, there was no... my mother was quite open about that and I'd feed 'er and do things with 'er, but I think there was too big an age gap.

*It's working. [Whispers something inaudible.] So, and your mother, (I'm going back again a bit); your mother wanted you to go into mainstream education. Can you remember the discussions about that at the time? Or, was it - ?*

No. It was just taken that I would go, and it didn't seem to be a big hassle like it is now. And, I mean, I'm a big supporter of inclusive education, but there wasn't a big, you know... there's a lot of talk about 'mainstream education is not inclusive because there's only one child in there that's disabled and that's not the right thing,' but I was the only disabled child in all the schools that I was at, and I didn't personally find it a problem, but that could be something to do with my personality per'aps, I don't know.

*Do you remember anything about the attitudes towards you?*

No, I always found it quite good and the children were really good, and when I was 13 and I was supposed to wear callipers, I used to go into school with them on and as soon as me mother 'ad gone I'd take them off, and then they would carry them from one classroom to the other and then I'd put them on before she came back.

[Interviewer laughs.] No, I didn't find it a problem and I've found the teachers were OK. There's a bit of a problem over things like sport, because obviously I couldn't do them, and I seem to remember that my school days were really happy.

*And what were your strengths, in terms of subjects? What did you enjoy?*

Art and Literature.

*And difficult ones? Or the -*

... missed about three years' schoolin' altogether so I missed my 11-plus. So I went to secondary modern school, as you did in those days, and I'd always seem to be tryin' to catch up.

*And was there any schooling in the hospital, when you were there?*

There was a bit, but nothin' very special really, no.

*What about attitudes [rustling noise] towards you in general? I mean, you talked about your gran having a sweet shop: that was when you were a lot younger I know, but do you remember anything about the attitudes of neighbours, of people you met?*

No, I don't really remember any bad attitudes, but I'm not sure whether that's because there weren't any, or because I've forgotten [laughing] because it's a long time ago.

*And, at that stage you said you were walking until - ?*

I walked – I never walked on my own – but I was able to walk with somebody’s arm till about 15 years ago.

*Mm. [Rattling noise.] That was coming to an end just then, was it? We’ve talked quite a lot about your parents. I mean, do you remember discipline or being told off or?*

Oh yes, I do remember discipline. I remember one particular occasion, I must ’ave been very young, when I’d obviously been cheeky and I was put to bed in my cot. And I don’t know how I did it, but I managed to climb out of this cot, and I was like crawlin’ on the top of the stairs, and my mother was so delighted that I’d managed to get out of the cot, that all discipline was out the window. [Interviewer laughs.] I remember bein’ disciplined at school, like everybody else – I remember bein’ caned, and clipped over the head with a plimsoll, as they did in those days. And I think a lot of the problems I had with discipline was the frustration of not bein’ able to do what I felt that I should ’ave been able to do, not because they were disciplin’ me, but because of the disability.

*And how would you react in those days?*

Mm. I’m not a moody person, I probably would have just had a bit of an argument word-wise. [Laughs.]

*And what about friends? Did you play at home, or did you go out with friends?*

I remember one winter when I was very little and we’d had a particularly hard winter, and because I couldn’t play out in the streets in the snow, I remember my mother bringin’ me in a big washin’ bowl full of snow, and playin’ with that. Toys and things were quite difficult to get hold of. I remember havin’ a doll with a celluloid face, and it bein’ put too near the fire and it meltin’, and I remember that any toy that I had that was actually broken always had to be got rid of: it was the way I dealt with things and I still feel like that now. As far as friends are concerned, yes I had lots of friends, they

came in my house and played – I don't remember very much playin' in anybody else's house though. I remember playin' marbles on the streets with friends and playin' in the garden, but it was mostly about them comin' to me rather than the other way round. And when I was in my teens, my best friend – 'er name was Adelina – we used to go to the local park, which was quite a long walk away, and on one particular occasion I was on my three-wheeler bike, cos I used to have a very big three-wheeler bike, and we used to tale this big wigwam and play artists. And anyway, it obviously had been rainin' quite a lot and my three-wheeler bike back wheel went over the edge of this, I call it a 'river'. (It sounds very grand. It probably wasn't a river but it was quite deep.)

**[End of Tape 1 Side A]**

**Tape 1 Side B [Track 2]**

*Yeah, you were just talking about when you were playing on your,*

Mm hmm.

*three-wheeler.*

So the wheel went over the edge and I went in, and of course everybody on the bank was sayin', 'Oh,' you know, 'get out,' and obviously I couldn't get out, so my friend was shouting, 'She can't get out, she can't get out'. I don't know what word she used, probably 'handicapped', I don't know, and anyway some woman obviously realised there was something wrong, and I remember seein' all these things like fish and weeds passin' pass me face, and she came in and dragged me out. And the next thing was, I was goin' home in a police car with my three-wheeler bike on the top, and my mother was out on that particular occasion so me dad felt the best thing to do was to stick my feet in a mustard bath – which seemingly this is what they did in those days so you didn't get a cold – and my mother came home to all the children in the street sayin', 'Your Anne's just come 'ome in a police car, she's nearly drowned'. Anyway, I didn't get a cold, my friend did get a cold who'd been nowhere near this river, [interviewer laughs] and she was banned from playin' with me for two weeks. And on one of my father's routine calls to one of his clients, as 'e was an insurance agent, this lady 'ad got all 'er legs bandaged up, and he said, 'Oh, what have you done to your legs?' She said, 'Well, soon as I rescued a girl out of Bramhall River,' she said, 'my phlebitis has come again.' And it was me, and she was tellin' him 'ow lucky I was, because nobody was takin' any notice of me. So I did get up to some escapades. [Both laugh.]

*You were born just at the beginning of the war, and you've told us a bit about the war: can you remember anything about things that were difficult, during that period?*

Well one of the things that was very difficult was keepin' me in shoes because, as I say, I was walkin' then and I dragged me toes and they soon wore out, so it was a search tryin' to get enough coupons together. And when me dad came home on leave, he used to put them on a last and put segs in to make them last a bit (they're like little silver things on the tip of the sole). And I used to hate these segs because they made such a noise when you walked: so yes, shoes were very difficult. I don't really remember much about [rustling in background] any difficulty in gettin' clothes, but I do remember the shoes were very difficult.

*And food?*

Food was very difficult. We used to keep hens, from day-old chicks, for their eggs, and we used to 'ave these. I don't know why we've got them indoors, but for some reason we've got them all in these cages. And I remember me mother had this really loud sneeze, and if she sneezed, they'd all stop dead in their tracks, whatever they were doin' they like stopped. And they were quite easy to die these chicks, so we used to put them in a little Dairy chocolate box in cotton wool, and we'd got a back to back oven and we'd put them in there and the warmth would revive them. I think it's possibly why I hate eggs now because we ate so many eggs, and when my dad came home his job was to wring one of the chicken's necks so we could eat it, and he hated it, and he never was very successful with it. We also used to have this thing called 'yellow peril' which was like a dried egg powder, and you reconstituted it and made it into fried eggs, or you could use it in cakes. We used to get our groceries once a week and my job was – we used to have a minute amount of butter, and this had to be mashed into the margarine to make it more flavoursome, and we used to cut all the rind off the bacon for some reason, I don't quite know why we did that; that was another of my jobs. So, yes, I don't really remember ever feelin' hungry, but the choice of course was very limited.

*And did you, you know, have pocket money?*

I remember havin' pocket money when I went to college, I'm sure I must have had it before that. I don't really remember it, but I remember then because I had half a crown, and on a Friday (I think we finished early on a Friday) we all went to the local theatre, which was called 'The Davenport' and we had a coffee, with this half a crown. I could do that, and I could go to the theatre, the cinema, once a week and buy some sweets. And it seemed to go on forever really, but that's the only real... I don't remember much else about pocket money. I know when I started work I wanted this portable radio which I mean in today's eyes it was more like a suitcase, but my father didn't believe in HP [hire purchase], 'e was very much against it, so my granny said that she would buy it and I would pay 'er back. And I had to pay her back till it was all paid up, you know, there was no lettin' me off. I didn't get any special favours, basically.

*Mm. And the secondary school is... It sounds as if you had quite an outside life by then – you were going off to the theatre and things.*

Mm.

*What kind of activities did you do in your adolescence, did you enjoy?*

I went to youth clubs as a teenager, and I went to the cinema. I don't remember an awful lot else really.

*Can you remember friends then, or - ?*

In my teens?

Mm.

Yeah, there one or two, but as I say they did drop off as they began to get boyfriends, or girlfriends, come to that.

*And then you met your husband,*

Mm hmm.

*or your husband-to-be.*

Mm.

*Can you tell me a bit about the circumstances: where you met him and got to know him?*

[Sound of movement in background.] I was workin' at a chemical pharmaceutical place at the time: I started my work in an engineering [dog barks] place, and I was there about two and half years, and then I got fed up with that so I decided to move to this pharmaceutical place. I hadn't been there long, when they decided to make me redundant (I can't quite remember why) [rustling in background] so I went to, it wasn't called 'The Job Centre' then but whatever it was called, and they didn't really know what to do with me basically, so they said, 'Oh we'll send you to St Loyes for trainin', which is a college for disabled people, and [talking together] I went there -

*This, sorry, can I interrupt?*

Yeah.

*Whereabouts was this?*

This was in Devon, just outside Exeter. I remember it very well cos it was a different sort of life for me: I was 21 at the time, and I remember sittin' in the corridor before everybody 'ad to 'ave a medical, and somebody sayin' to me, 'Have you got a boyfriend?' and I said, 'No.' 'Oh well, you soon will be when you've been 'ere a bit.' Anyway, every month they used to have a dance, disco, and they opened it up to the general public. And on this Topsham Road, I think it's still like it today, there's an

[rustling in background] Army camp and a Navy camp, so they all used to come in as well, and this was the highlight of the month because this was when you could stay up till midnight – every other night you could be in bed by half past 10. And I met two people at this dance, and they both said they would take me out, and I agreed to both of them because I thought neither will turn up. [Interviewer laughs.] So I went out with one, and was told that the other one had turned up as well, and it was like, well, it was just, I can't describe it. It was like a different world to me, and I 'ad quite a few boyfriends. One particular one was a watch and clock repairer – he'd trained there and he used to go back for the dances I think. And I started there doing comptometer operating (it's before the accounting machines), but I [rustling movement in background] was only allowed to do it for six weeks when they decided that it wasn't the course for me. I was handlin' it perfectly OK, I might not have been usin' the right figures but I was doin' it. But they said, 'No it wasn't the right course', so they decided to send me home. Well I was goin' out with this watch and clock [repairer] and I was absolutely devastated because I could see what was goin' on there, and I knew that once I'd gone he'd be with somebody else. So I can remember goin' home and cryin' me eyes out. I used to go home on the train on me own. And I remember durin' the time that I was home, knittin' this Big Ben jumper which was all the go then, and it had seagulls over the back: it sounds dreadful but it was the fashion then, [interviewer laughs] and of course, when I went back, yes, he was with somebody else. And durin' that time, my ex-husband had started the college, and I went because I didn't think they would send for me again, I thought, 'Oh that's it, I won't be goin' back there.' Anyway, they then put me on the PAYE [Pay As You Earn], an accounting course, which he'd been on some weeks (I think) previous to me, but 'e was goin' out with somebody then, who ironically they kept gettin' locked out, so she used to climb through my bedroom window. Whenever I went out and got locked out, I was always up before the matron because I couldn't climb through the window. And they had some really odd rules because no married women could be part of the college but there was quite a lot of married men, so there was a lot of goin's on between the married men and the single women, and it was 'ard cake really, I mean, when you think of it, you know. This would be in the early sixties. And so then I met my ex-husband and I remember 'im comin' back for Christmas with me – we 'ad to pick 'im

up from the railway station because he lived in Market Harborough, I lived in Stockport, that's how I came to live here. And I can't quite remember why 'e was still there, my course finished before his, now I don't know why that was really cos I thought 'e was on it when I got there, but p'raps, he was on a longer course, I can't remember. So 'e wanted me to become engaged to 'im, but I wouldn't become engaged while I was there; I 'adn't known him that long, and I just thought, 'Well when I'm gone, that'll be it, he'll be with somebody else,' so I wouldn't get engaged and I came home then I got a job more or less right away. And he used to travel from Market Harborough to Stockport in his three-wheeler invalid carriage, and in two and half years he went through two engines, [rustling noise] doin' the distance backwards and forwards. [Interviewer laughs.] That was it really.

*[Laughing.] Yes. Can you tell me a bit more about the college? You went there when you were 21?*

Mm.

*And it was a college?*

It was called St Loyes College for Disabled.

*And people went there for, short periods, long periods, or how did it work?*

The shortest periods was six weeks, or you could be there up to two years, dependin' on what... it was a bit like an apprentice scheme really,

*Right.*

dependin' on what you were doin'. I mean there were all types of disabled people, I mean it wasn't the best settin' because the women's quarters was down a big hill, and I remember once I could never push meself, and somebody lettin' go of me, and me goin' down this hill and comin' out the wheelchair. It was quite a frightenin' place

really because there was no care, as such, and you 'ad to basically look after yourself, which I'd never really done. And I was in a room, with (I now know, I didn't realise at the time) someone with learnin' difficulties, and they were really quite happy to do my ironin' so that was great. [Interviewer laughs.] And it was, you'd go to the loo, somebody'd help you, but you'd often be left there because people'd forget you were there: it wasn't ideal by any chance. I remember, I was really quite well off there because we got I think it was £2.80 spendin' money, which was probably not much different than the wages I'd had when I was in work in those days, and which I used to give my mother half. So, havin' that to spend on meself was like Utopia. And we used to go into Exeter on the bus, and every month we'd have our hair done at, ooh I can't remember the name, it was 'something Henry's', it was really popular at the time, and looked round the shops and get ourselves dolled up for the disco at the night. [Interviewer laughs.] And people used to have their three-wheeled in, I took my three-wheeler invalid car there, and it was nothin' to see more than one person in those cars goin' down the road, and the police didn't seem to bother – we would stick people in with us and nobody'd really bother. And then I remember there bein' a young man come from Sark, and he asked me if I'd go up a ride round the grounds of St Loyes with 'im in this invalid car, and I got caught bein' in this car with 'im and I was about to be expelled, which I found most annoyin' because nobody thought of expellin' him for invitin' me in there. Anyway I didn't get expelled, but I was always gettin' told off for one thing or another.

*How long were you there, do you remember?*

I was there nine months.

*It sounds quite a liberating time.*

Oh it was a liberatin' experience, by Jove it was. [Laughs.]

*And did you cook for yourselves as well?*

No. All the meals were terrible, we used to call them 'weevils' [interviewer laughs] but I'm sure they weren't. But we used to 'ave these awful fish cakes and there were these dead things in them, [interviewer laughs] I don't know what they were, they were absolutely dreaded, but when we got a roast dinner, which was usually some sort of awful fatty lamb, because it was much better than anything else we thought it was wonderful. And then my mother used to send me cakes in a big cake tin, and we'd share those sort of things out, and we used to buy quite a lot of things to eat out of our pocket money. We used to go to the local pub in our invalid cars – I mean there was nothin' to do with drinkin' and drivin' then, didn't come into it. [Both laugh.]

*So can you tell me a bit more about the invalid car? When did you have to take a test [talking together] and so on?*

Mm. Yeah, I took a test.

*When did you get one?*

When I was 16,

*Right.*

and when I was at home, which was a similar test to a motor bike test. Mine was an electric one so it went quite slow, and it was a terrible day, and because the side windows were plastic you could 'ardly see out of 'em. And I remember goin' up a one-way street the wrong way, and the poor man waitin' on the street corner askin' me where I'd been cos I was so long. Then you had to do an emergency brake with the person in the car and I pulled the brakes on so hard, he nearly shot through the window. He passed me – I think 'e was so glad to get rid of me really.

*And how long did you have the invalid car for?*

Well the first one I had, well I can remember it was really awful, a black thing, and when I was 16 my parents moved house to Bramhall from Stockport, which is quite a posh place. I don't know why me mum decided to buy this bungalow cos it was most unsuitable for my needs because it was up a really steep drive, and we used to take the invalid car up to the garage at night, and I used to leave the motor on forward so the next day, when you came back, that helped it goin' backwards too quick. Anyway, for some reason one particular day, I don't know whether someone had moved it or not, the gear stick was in reverse, so the more I pushed on the tiller, the faster I was goin' down the drive. And I came down the drive backwards, [laughing] about 90 miles an hour, spun it round in the road and ended up with the back end over the [interviewer laughs] garden wall. I was on my way to work, but I was so insistent that I would go to work, that I would definitely go, (which was in Stockport, quite a long way from there). Anyway off I went, but I when I got to the office, when I came to get out my legs just went to jelly, and then I proceeded. And I got a better one, as they more modernised them, but when I came to Market Harborough to live, my ex-husband wanted a car, because in those days you got a Mini – if you gave up both your invalid cars, you could 'ave a Mini, if you were a married couple. Well I wasn't too keen on this because I felt that this was my independence, so I was workin' at the time at a construction company that made golf buggies, so I approached them and they bought a chasse: is that right? Anyway, the body, and made me a three-wheeler car out of it, which was really good, but it tied me to the firm. I never got any increments because of this, and when I left there was only one person who could actually repair it and I always felt quite beholden on 'im, so it was a good move in some respects but not in others.

*You've mentioned various jobs: can you just go through some of the jobs, the work, you've done, cos there was some before you went down to St Loyes,*

Mm hmm.

*and then you've worked since then, of course.*

Mm hmm.

*Can you just remind me a bit?*

Mm. Well I started when I was 15 in an engineerin' works, and I was an invoice typist, with about 50 girls in an office, and you had to reach a certain number of invoices that you could type in a day – it was over a hundred – and they had, like, a woman manager who walked up and down all day, and there was no talkin', I mean it was just so strict. And you had specific times to go to the toilet, and I always remember at this stage that I always 'ad terrible periods and I was mortified that I'd got to go in... I can't quite remember the mechanics of it, I think I could sort myself out but, I remember my granny makin' me this, it sounds 'orrendous but it was a purply-blue, it was like a taffeta sort of skirt that I always wore when I was on my periods because if anything came through, it didn't show on it. And then after that, I went to the pharmaceutical works where I was on an accountin' machine, and there I remember we 'ad to wear these white overalls, and they'd got these rubber buttons on that you put in when they'd been to the laundry, and there again I was absolutely always mortified when I was on my period that some of it would come through on this white overall. Periods seemed to play a really big part in my life, I don't quite know why this was. So then I went to St Loyes after that, and when I came home, I 'ad a job to get a job, but I got a job within three weeks, and [engine noise in background] I worked for Bamfords, which was a ship building company, which was quite a long way from where I lived. I went in me invalid car, [interviewer laughs] and I did wages there, and then from Bamfords I went to Tates Electronics that made TVs and I went back to audio typin'. And it's from there that I got married, and then I came to Market Harborough, and I was only out of work again about three weeks, and [rustling noise] I got a job again on an accountin' machine at the place where they made my buggy, my three-wheeler invalid car. And then from there, basically I got fed up with jobs. I think it was because they were borin', because they weren't stretchin' me, so I kept movin' on, which did make it quite difficult cos it was a task gettin' a job. And from there I went to Symington's Corset Factory where I was in the accounts department, and then I went to E.T. Pearson's; I really liked that job. That was as an audit clerk,

but I had a terrible boss, who nearly made me 'ave a nervous breakdowns because 'is expectations of an audit clerk were so much that I was expected to be able to present the accounts to trial balance stage, which was not what I was employed to do.

[Rustling noise.] And we had to do... oh, what d'you call it, when... Oh, I've forgotten... when people buy cars and they all that out each year.

*Oh – depreciation?*

That's it; and I couldn't get me head round this and I used to get really stressed out about it. And toilet came into it there because they'd got this toilet, it's in Market Harborough, it was an old buildin' and they'd got this toilet for men and women, I don't think they'd get away with it now but, and if 'e knew I was in there, I couldn't lock the door and he'd hammer on the door. Things like that, anyway, this drove me to... I had to leave basically. So then I went to Tungsten's which is the battery firm in Market Harborough and I did audio typin' then, and then I went to work at the mushroom farm, and I was asked if I'd be taught how to do the wages because Elsie, the one who did them, when she was on holiday they had nobody to do them. Well, my husband of then, he did wages and I wanted to do them the way he did them, but she wanted me to do them the way she did them, [interviewer laughs] so that didn't go down too well, and basically it got me so worked up, one day I walked out. And then I didn't go back to work. Well, our financial situation was such that I didn't actually need to, and it was in the seventies when jobs were really difficult to get, so then I 'ad three years at home before then my husband left me.

*[Sound of aeroplane in background.] And, I mean, all these jobs: you found it difficult sometimes to get a job, but do you remember, were you aware, of being discriminated against or people having attitudes towards you, or did you find that once you got the job it was...?*

I think once I got the job it was OK. There was a lot of reliance on other members of staff to assist me to the toilet and things like that, but I always felt that I wasn't really

used to my potential. They were quite mundane jobs, I'm sure that lots of disabled people tha' been able to do a lot more.

*And accessibility? I mean, I guess some of these premises were not very*

No.

*well-adapted. Did you - ?*

Well a couple of steps were up to the accountants, but I could walk in those days. I'm just tryin' to remember. I don't remember usin' my wheelchair at work, cos I'd go in me invalid car and then someone would walk me in to the desk. I was able to walk then with somebody, so I never actually had to use the wheelchair at work.

*And you could manage stairs, or steps?*

Just a couple. If it was just two up, I could just about manage that.

*Because it's often those kind of things that defeat, you know: accessibility is often a huge problem with work.*

Mm. I think it was people's attitudes gettin'... once I'd got through the door and got the job, I could prove... in fact I probably gave a 150 percent. I didn't have time off work, I was, you know, I'd go with a cold, whereas some people'd be off. So it was just actually gettin' through the door, convincin' them that I could actually do the job.

*And, the first jobs? I mean, had you had any exams? Had you passed exams at school?*

None. I got me RSA One, Two in shorthand and typin' and bookkeepin' at the college that me parents paid for me to go to, that's the only qualifications I'd got.

*And that's where you started?*

Mm.

*Mm. Quite determined. [Laughs.]*

Mm.

*[Laughing.] You were talking a bit about the problems about toileting, and problems about periods and so on. I mean, as a girl growing up, did you have any particular difficulties, or do you think you went through adolescence in the same way as [talking together] other people?*

Well funnily enough, me mother was really odd about things to do with bodily functions and sex because I remember findin' a sanitary towel and wantin' to use it as a pillow in me pram, and me mother explainin' to me why you couldn't do that. And she'd explained to me, you know, about havin' periods so I don't think it came as a shock to me, and when she was pregnant with my sister that died, she would be quite open about that. I don't know whether it was the times we lived in, but we didn't seem to ask about the mechanics of how the thing, the seed, got there. We were quite content to learn that it did. We didn't want to know much more than that. I've forgotten the question you asked me.

*Well I suppose, really, about growing up and being a young woman growing up, particularly.*

Well, I mean, as far as puberty and all that sort of thing was, I mean I was quite late, I was 16 before I started me periods and I was desperate to start them but once I'd started them, I wished I never had. [Interviewer laughs.] I'm sure most women feel like that. I don't think I was encouraged to 'ave any sort of sexual feelin's, because me mother didn't see me in that way, until I went to St Loyes College. I mean I did have one boyfriend before that but I – [laughs] this sounds terrible to say this and it's

very un-PC [not politically correct] – but lookin’ back, think he probably wouldn’t ’ave found anybody else other than me, [both laugh] if I’m just bein’ truthful.

*So you were never taught about... You never had sex education? [Talking together: inaudible.]*

No, there was none of that in school in those days, no. Anything that I knew of, I learned from what my mother ’ad told me or what I’d ’eard other children tell you in the playground or whatever. But I don’t think that that did me any harm, and I feel that too much explanation goes on these days, personally.

*And what about when you met your husband? Was that straightforward?*

In what respect?

*Well I suppose, you know, in the way you got on with each other and learned about each other and so on.*

Yes, he’d been engaged before, but just before his 21st he found out he’d got multiple sclerosis and she left him basically. And he told me that one of the reasons that she left him was that she’d been to the doctor’s and he told ’er that they wouldn’t be able to ’ave any children, and I sort of accepted that as bein’ a bit farcical and possibly an excuse for ’er wantin’ to get out of the relationship. Well, what is there to [both laugh] tell, really?

*And you were together for, well you were married for - ?*

Twenty years.

*Twenty years.*

Mm.

*Yeah. Mm.*

And I found out that actually he couldn't have any children, but he never told me that.

*Was that something he was aware of, do you think?*

Yes. Definitely. He must 'ave been aware of it.

**[End of Tape 1 Side B]**

**Tape 2 Side A [Track 3]**

*I'm interviewing Anne Pridmore at her home in Market Harborough, on July 15<sup>th</sup>, it's 2005, and my name is Anne Austin. Yes, a couple of things that you wanted to include about your earlier childhood...*

Mm.

*Tell me a bit about, perhaps, the girl in hospital?*

Mm hmm. As I said earlier, I was in hospital when I was five for 18 months, and I told you before in the interview that when my mother visited me she found me with my legs over the side of the bed, with both heels drippin' onto the floor, and this was one of the reasons why she took me out of the hospital – because they'd put plaster of Paris on splints on my legs without any wadding. And she found out later, that the girl in the bed next to me had had to have her leg amputated because the plaster had actually ate into 'er hip, and this had caused her to have her leg amputated. So it wasn't a very pleasant experience, it must have been extremely worryin' for my mother who'd put, you know, me in the hands of what she saw as the professionals, and what she felt was the best for me. And I went in there bein' able to walk across a room, and came out not able to sit up. And something else I forgot to record was the short time I spent in a special school: I don't remember a lot about it, it was when I was nine years old and I remember goin' to school (my father had to take me cos it was such a long way in the car), and bein' absolutely terrified about this school. I remember, we had an old Ford Standard car, and there was a little hole in the back floor of this car, and I was always desperate to go to the toilet when I got there, I think it must have been the nerves of goin', so we used to have this potty, and I used to go for a wee on the potty, and then we used to tip it through this hole cos it was the only way to get rid of it. And even havin' done that, it was quite often that as I was goin' in I'd wet meself, and I think it was the fear of this school. I can remember that we used to start quite early in the morning, and I was in callipers at the time, and I had two walkin' sticks that were clipped together with two pieces of metal, and we had to walk

from goin' from the bus, and then we went into the breakfast room: there seemed to be an awful lot of children there. And I remember this walk from the bus was absolutely terrifyin' cos I was always frightened that I was goin' to fall over. And I remember something about some rooms that were never gone into and how, as children, we went into these rooms, and they were all left as they'd been left durin' the war, and it turned out that this place had been some sort of hospital, and the iron bedsteads were still there, and nothin' had been done to them. I don't recall this bein' a very pleasant experience, the whole period, I think I went there for about six months. I never learnt a thing, the emphasis was on physiotherapy and gettin' everybody to walk. As for the academic side of it, it just wasn't there, and I think that my parents realised that it would be better to take me out and put me back into mainstream education and this is what they did.

*I wonder what the reasons were that they chose, you know, that they suggested you went there, because you'd had quite a successful period in primary school, hadn't you?*

I can only think that the reason my parents sent me there was that they'd had advice from the education. I mean, I don't really remember or know the reasons, I mean, it could have been that I was just a bit too much trouble for mainstream education and they were tryin' to shift the responsibility. Or it could have been comin' from the medical profession who thought I'd benefit from the physiotherapy, I'm not really sure.

*But your feelings then were – you didn't like it?*

No I hated it, and found that there were a lot of people there who were content to play around and not do any academic work, and I felt that it was just a waste of my time bein' there.

*And do you feel that now as well? Do you feel any different about it now?*

Oh I feel very strongly that to put children into special education is the wrong way round, not only from an academic sense. I know I 'ave plenty of friends and colleagues who were brought up all their life in special schools and the main thing that they suffer from, if you like, is the lack of any social skills. [Voices in background.] They talk independence at any cost: you know, if it takes them hours to get themselves up and dressed in the mornin' that's the main thing, but as far as havin' any social skills, and a lot of them will tell you, that it's had the worse effect on their lives than the lack of any sort of education.

*Yeah. And we move on from last week to meeting your partner and your relationship with him, to when you got married and so on. Can you tell me a bit about how you met him and how you became friendly and so on?*

Mm hmm. I met my partner when I went to St Loyes College in Exeter, which is a training college for disabled people. We were both on the same book keeping course. I was there three months before him, on a previous course, but they decided that that wasn't the right course for me – I think I talked about that on the last interview. So I met him in 1961, and he came from a place called Market Harborough, which I had never heard of at the time: I lived in Stockport in Cheshire. I came home before him and got a job in an engineerin' works, doin' wages and accounts and he came home after that. He lived in Market Harborough as I said, and he used to travel to see me every fortnight in his three-wheeler invalid carriage. It was a petrol one, and durin' the two and a half years that he came to visit me, he wore two engines out doin' it. I went to see him durin' this time as well. He was one of nine children, he had eight sisters (which is funny cos so did my father), and one of his sisters was havin' an engagement party so this was my first visit to Market Harborough. And I came up on the train on this occasion, and I remember it was the same time that Robert Kennedy was shot, and it was goin' along in the train, 'Oh, he's been shot,' and I can always remember this occasion. And I was met at the railway station, by my future mother-in-law – this is when we were engaged – and I remember feelin' a little bit like some new ornament that had been brought into the house, and I can remember one of my sister-in-laws' husbands takin' a photograph of us on the settee. It was a very strange

encounter for myself, because I had been brought up with just one sister, that was 11 years younger than me. Brian's father went out of the family when Brian was two and a half, so his mother 'ad struggled to bring them up on her own, and she was a very hard worker. She did all sorts of jobs to eke out the family income, I remember one job she did was to wash and iron the tablecloths for a local restaurant, and these were red, and it was OK if it was a good dryin' day, but if it wasn't they were all strewn round the house because they didn't have things like driers in those days. Anyway, I just came for the weekend that time but then, in 1964, we decided that there was no way we were goin' to get any housin' accommodation unless we decided to move in with my future husband's mother in Market Harborough, and then we could say that we were overcrowded, so in 1964, we got married. We had a bit of a problematic weddin' because I didn't want to have any children at the weddin' and my husband's family said none of them would come if I didn't invite the children, so I had to have these children and we'd wanted them to hire a room so they could go to this room before the weddin' but they all came to my house, and like I was tryin' to get ready amongst them all eatin'. I seem to remember them eatin' fish and chips and it was just, awful. Anyway, it was all the big white weddin', and it was a good day although it seems to go in a flash. And my sister was one of the bridesmaids, who was the exact same age as my husband's sister (who were 13 at the time), and then I had a friend as the third bridesmaid so, oh, and we then went off to spend our honeymoon in Blackpool. Goodness really knows why we went there, I don't really know. I think it was because there was a tram system which we felt we could get onto, and we could go to lots of different shows, and we stayed in a very posh hotel in those days called Hydro Springs on the front. I mean it's quite laughable now because I think it cost us 60 pounds for the week. Anyway, for some reason, I'd done all the arrangements to book this hotel, and my mother rang up the second day we were there to see if we were all right and she asked for Mrs Pridmore which was my married name, and she was told that they hadn't got a Mrs Pridmore stayin' there. So of course she was extremely worried so she said, 'You must have,' so they looked again and they said 'Oh, well we've got a Mr Pridmore and a Miss Broomhall stayin' here'. So this explained why we hadn't had the gift from the hotel for newly-married couples because they didn't think we were married, which in those days was quite awful.

Anyway, we were havin' quite a good time till the middle of the week, when my mother decided to come and visit us. Can you imagine – on your honeymoon? And everything was goin' fine till then, and she was pushin' me down the front for some reason and managed to tip me out of my wheelchair, so that wasn't too good.

Anyway, then I went back to Market Harborough to live with my mother-in-law. I have to say, it was eight months of purgatory. I think that she had decided that Brian wasn't goin' to get married, and he of course was 'er only son, and she was goin' to keep him at home forever. And of course he was quite a good little earner because he originally 'ad trained to be a train driver on the steam trains, but when he got MS [multiple sclerosis] when he was 21, he had to stop that, so 'e'd been to St Loyes when I'd met 'im and taken up accounts and got a very good job with what was then The Rutcliffe and Wycliffe Society for the Blind in the accounts department. I forgot to mention as well, that when we got engaged, when 'e went to get the money out of his bank account to buy the engagement ring, she'd taken the majority of it out of his bank account, so when we got married we didn't pay any board for some time in order to recuperate the money, and this didn't go down very well with the remainin' siblin's who were at home who were havin' to pay something towards their keep and we weren't payin' anything for a time. Anyway, the time dragged on, and although we'd got our names down on the housin' list, nothin' seemed to be workin', and Brian wasn't very pushy and didn't bother to go down and sort it out, so I said to 'im, 'If we're not moved by the Easter of the followin' year...' (we got married in the July) I was goin' back to Stockport basically. So that soon shifted things, and we did get the bungalow that I still live in now, some 41 years later. At the time, we thought it was marvellous to get our own place, but havin' lived 'ere for all those years, I now see that we were basically a young couple dumped into an old peoples' ghetto, because I was a young bride of 23, and the nearest in age was somebody of 65, and they ranged from 65 to 90, and although I'm sort of a pensioner myself now, I don't fit in any better now than I did all those years ago. So, whilst we'd got our own home, it wasn't the ideal situation. I went to work, I got a job three weeks after I'd got to Market Harborough. I just remembered something about when I went to stay with my mother-in-law: at the time (I don't know why, I think because it was more convenient to my mother) I used to be incontinent in the night, so my grandma 'ad made me (and she'd

carried it on) these adult, like, rubber knickers. And I used to wear towels like nappies in these towels. Anyway, this continued while I was courtin' at my mother-in-law's and she used to be really funny about these and make a big issue of it, and she used to give me about two inches of water to wash them out in the morning. And on the first week that I was livin' there, they had a bath night on a Friday, and of course they didn't have a lot of hot water, so they used to go in the tub and top the water up. Well I found this absolutely horrific, and I refused to do it. I said, 'Unless I can be first in the bath, I'm not havin' a bath,' and of course that got me the name of bein' a bit of a snob by the rest of them. There was, at this time, three other children still livin' at home and we'd got one bedroom – 'is mother had got the other and the other three were in the other bedroom cos it was only a three-bedroomed house, and she'd brought up nine children in that house, and Brian had always had a room of his own, because he was the son, you know, he was thoroughly spoilt. She actually used to get him cooked supper at night when I lived there, but not for me or any of the others. That was every night: he'd have cooked supper. And another thing about when I lived there; I'm just rememberin', she used to delay helpin' me up the stairs, because she didn't want us to go to bed. I don't really know why, she'd say, 'Oh well you like this programme, don't you Brian? You're goin' to watch this,' and it used to get later and later. So when we came into this bungalow that I live in now, I suppose it was absolutely great. She wasn't very pleased about it and although it was new property, we had to come and clean it out, and she didn't want to have anything to do with it, [talking together] so...

*Can I ask you a bit, I mean, it sounds as though that was a very difficult time, living with your mother-in-law and your brothers-in-law, sisters-in-law...*

Mm.

*Can you tell me about her, at that time, and how you feel about that now?*

Well, it was such a different environment than I'd been used to, I mean we'd always had holidays, and we had a car. I suppose we 'ad a better standard of livin' if you like,

and I can remember the first meal there, cos there was quite a few of us, there was probably some of the other sisters came as well, and I can always remember this meal because we 'ad a mixed grill – egg, bacon, tinned tomatoes – I'd never 'ad tinned tomatoes in me life till I got there, [interviewer laughs] and I've never seen such an enormous tin of tomatoes in all me life. And the thing that stuck out to me was that although I felt that in many respects I'd 'ad sort of a spoilt existence, the food that she put on the table was much better than what I'd had at home. All the money seemed to go in to providin' a good table, and never, ever did she sit down to eat a meal with us. She'd be 'aving a bit out of the pan, if it was dinner, as she was goin' along. You never ever saw 'er sit down and eat a meal. And on a Friday night we always ate our main meal at dinnertime: most, the girls came home from the factory – they all worked in the local factory, at either Symingtons Corset Factory or Symingtons Soup, and they were all on the conveyor belt, so of course me and Brian bein' in office jobs, that was like really snobby to them – and on a Friday night she used to get a great big cottage loaf, and she'd have a portion of potted meat, there'd be a cucumber, tomatoes, lettuce, bananas, and whatever, and you had to tell her how many sandwiches you wanted, and if you underestimated it you couldn't have any more, and if you took a bit more than you could really eat, you'd got to eat it or else you were in big trouble. And it was just very different, and I think she did resent me bein' there; she resented the fact that I had taken her son, that was quite obvious from the beginnin'. However, lookin' back on it and later, I always think that she was a very hard worker, and she 'ad a struggle to bring these children up, and she did the best for 'er but she definitely resented my presence there.

*And, how far do you think your disability was affected? I mean, what was her attitude? Was there any difference in her attitude towards you, because of your disability, do you think?*

I don't know really, because she'd been used to Brian bein' there, cos he'd been off work quite a long time before 'e went to St Loyes, and she'd been used to havin' him there. I think in a way she quite liked that because she'd got his undivided attention. I don't think it was her choice that he'd gone away to St Loyes College, I don't quite

know 'ow that came about. So I don't really think she'd got an attitude to my disability, excepting that we had an outside toilet and there was always arguments about who was goin' to take me to the toilet, and I was often left there because nobody'd take me back. And one of my future brother-in-laws, who actually was my best man, cos I walked at the time he'd always come and take me out the toilet, but it used to be quite a dread because my husband couldn't do this, because 'e wasn't able to walk me unaided. So yes, it wasn't a very happy time.

*It's difficult. And then you came here, and what was the attitude of the older people around? What was the impression you got of how people treated you?*

Well when I first came here, I 'ad a very good neighbour called Win Muggleton and she was excellent to me. She must 'ave been nearly 80 at the time, and I used to come home from work and she used to come out to my invalid car and help me in, and she'd empty the bins and prepare the vegetables and things like that. And then, later on, we 'ad neighbours called George and Emily, and they were very good to us. I seem to feel that it wasn't quite so bad when Brian was here, it was when 'e left that things went really wrong.

*And that was some years later?*

Twenty years later. Mm.

*And how was it for you, being a young person amongst older people?*

I think because I was in full-time work up to 1979, I didn't really notice it so much, because by the time I got home I was doin' the meal and such-like and we 'ad our own life. In fact I wasn't really aware of bein' a disabled person in those days because my life was as the same as anybody else – we went to work, we 'ad a reasonable standard of livin', we went out socially to the pub for meals, we began to play bridge – so the barriers that I faced when my husband left me were not there.

*And do you have any contact now with your in-laws or your sisters-in-law? [Talking together: inaudible.]*

Well, my mother-in-law has been dead some 12 years now, and the only person that 'as stuck with me, if you like, is Brian's sister Beryl. She comes to see me quite regularly, about once every other week and she just stays half an hour. I think that the reason that this has happened is that I've never really mentioned anything to do with Brian goin' to her, because after all, it's not her fault, you know, what her brother does, and I think this has kept quite a good relationship. But unfortunately, she's quite ill at the moment, and she's had cancer and she's got secondaries, so it's not looking too good for her. But over the last 21 years she has kept in touch with me, but it's the only one out of eight; and when you think that we didn't have any children cos my husband couldn't have any, and I used to have all the 26 nephews and nieces round, and in fact one of them left home and came to live with me for some time, it is quite sad that they've treated me as they have.

*Mm. So here you were, a young married woman, and you were working and so on – can you tell me a bit about how life was for you both then?*

Yes it was good. I mean I can honestly say that I had a good, happy marriage for 20 years. We went to work, we went out, we had friends, but most of the friends that we had were instigated by myself. I was the organiser in the relationship and, yeah it was a good time.

*And, I mean, I don't know whether you want to talk about how things went astray or how... [Talking together: inaudible.]*

Yeah I don't mind talkin' about it. It was during June of 1984, I noticed a difference in him: he seemed to me to be losin' weight, I thought he was ill. And when 'e came home... I'd given up work by this time, I gave up work in 1979. I'd been made redundant and it was really difficult for anyone to get a job, let alone a disabled person, so I decided not to bother because we didn't really need the money. Although

havin' said that, I found it quite difficult havin' no money of my own because I'd always had some money, and I took up doin' the Open University [OU] in 1979 because I didn't want to vegetate. Now Brian, my ex-husband had no intention of doin' this, but when I started to do it, he definitely felt that he'd got to do it too, so he did it at the same time; which was OK when I was workin', but then after that I'd been able to do my studyin' in the mornin' and when 'e came 'ome at night, I wanted someone to talk to and 'e had to then get on with his studies.

*You were talking about how things began to go [talking together] astray.*

Oh that's right, yeah. So I mean it's easy to look back on all the events and try to put your finger on what it was that went wrong, and I don't really know the answer, but I noticed that 'e was doin' an awful lot of sighin', I thought 'e was losin' weight. And I had a friend of mine came to stay with me called Hannah and I said to 'er, 'I want you to tell me whether you can see any difference in the way Brian is,' cos I didn't know whether I was imaginin' it, and she said, 'Yes, there's somethin' not right.' So after the week she stayed with me, that followin' weekend I challenged 'im about it and I said, 'There's something wrong, Brian, and I can't go on like this.' There was no affection, we'd stopped havin' any sort of sexual relationship for probably about three months, and I got up on this Sunday mornin' and 'e gave me a letter that he'd written six weeks before, and basically sayin' that he wanted to leave while he still loved me. I mean I can't really understand what that means, but when I asked 'im why he'd taken him so long to give me the letter 'e said that 'e didn't want it to interrupt my Open University exams. Well we were both doin' the exams, and with hindsight now, I think it was more about interruptin' 'is own studies. So I persuaded him to go to Relate: I think it was called 'marriage guidance' or something in those days, and I had to go to summer school durin' that time at one of the universities, and he'd started goin', and when I asked him how he was gettin' on he didn't really want to tell me much about it. And then the lady came to see me here and then we had sessions together, but it would have been better to say from the beginnin' that he'd no intentions of makin' it any different because 'e'd made his decision to go. So as I say, I found out. I mean we went out for our weddin' anniversary on the 11th, even

though 'e'd told me 'e was leavin', and 'e bought me a present (I can remember it very well), and then we lived together from then till October, and that was very difficult because I thought I could persuade 'im differently. I think I never believed that he was goin' to go and what made it worse was anyone I told didn't believe it either, even 'is sister, because people thought that we were ideally suited and that we'd always looked happy together, so nobody seemed to believe it. At the same time, I spoke to Social Services and gave them three months' notice, because they'd need to provide me with some sort of care, and 'e went on the 31<sup>st</sup> October. And three days before 'e went, they came to visit me and basically told me they didn't know what they were goin' to do with me. At the time...

**[End of Tape 2 Side A]**

**Tape 2 Side B [Track 4]**

*You were talking about Social Services coming to visit you.*

Yes, well three days before Brian left, they decided they didn't know what to do with me, so they came and told me that, so they asked me if I knew anybody who would look after me. Well it's a tall order really, isn't it, to ask anyone to look after yer? Anyway at the time I used to have this mobile hairdresser who I'd got quite friendly with who lived down the road, so they said, well, could I approach her. So I said, 'No I couldn't, but you could,' and I said, 'You'll have to make it some sort of business relationship'. So they went and asked 'er if she'd come in the morning to get me up and to put me to bed at night, and that was all I started with. Now, at that point I was 44 years of age, and I'd never, ever been left in a house overnight on my own, so it was quite scary. Anyway, that worked quite well. I did everythin' else myself, I think that my sister-in-law still came and did a bit of cleanin' if I remember rightly, and I wasn't workin' then. It seemed a very long day, and I can remember feelin' a sense of complete aloneness. My friends were very good to me and they took me out, and durin' this time Brian continued to visit me, and we both played bridge at the same bridge club. We'd never played as partners because we thought that wasn't right, so 'e used to take me to the bridge club, and then he'd go home his separate way and somebody would bring me home. And I remember watchin' the clock and thinkin', 'He's gonna go home and he's not comin' back with me,' I always remember that. And when I came home at night, because Pat was down the road, she'd come and assist me to bed. This was the girl that Social Services... Anyway, for this they paid her the grand sum of £12 a week, and she had a little girl, quite a small child at that time, and when it came to the winter, her husband (who was a grass cutter for the council) used to have to go on gritting, so he had to go out at night, so she couldn't do it at night. So then they decided to get a home carer to come and do the... no the district nurse, that's right, came at night. Well the district nurse could come any time between eight o'clock and midnight. [Something whispered: inaudible.] Well no, it's not a flexible lifestyle to have so you had to stay in, and the first time the district nurse came, she came at eight o'clock, and I went to bed. Well, I couldn't stay in bed from

eight o'clock till nine o'clock the next day, without wantin' to go to the toilet, so this was a big issue for me. So I taught meself to get in and out of bed. It was quite dangerous because I was in the wheelchair, I had to stand up and hold on to the bedrail, swing round, and I had to lift my legs into bed, and it would take five or more attempts to get them in. Anyway it was better than bein' dictated to, so mostly I would let them come and get me undressed, but then I'd go to bed when I wanted to, but it was difficult to 'ave any sort of social life, well it was impossible. When Brian stopped visiting me when he met his wife now, I did still go to the bridge club and I used to come back with my bridge partner, and then I had to get myself undressed and into bed, and it used to take me absolutely ages. And because I was on a limited income, because I'd been thrown onto income support, I couldn't run the heatin' that much, and I remember how cold it was. I used to get me shoes off with a, it's called 'a helping hand', people use it to pick things up and I used to poke them off. I used to get the person who'd brought me home to untie me shoe laces sometimes, if I felt I could trust them to do it, and then other times I'd do it meself and it used to take me absolutely ages, and I used to wear stockin's so that they'd come off rather than tights, because I couldn't get them off. And then, around this time, Pat from down the road decided that she'd 'ad enough of it, which I don't blame 'er, because she was gettin' a pittance for doin' it. So that was the time when I was thrown onto the statutory services for all my support, and the first time they sent a home carer in the morning, she refused to get the bread out of the pantry because she said it wasn't on the care plan, so it was just absolutely dreadful time. I forgot to tell you that I had a dog, my first dog, three days after Brian left me, cos I always wanted to have a dog and he said we couldn't look after one. So I decided I'd have one, and I name it an anagram of his name – Ribbon – and he came with me to pick the dog up and I can always remember that one of my neighbours' grandchildren stayed overnight with me, the first night with this dog, and of course it was goin' into November then, it was bitterly cold, and I can remember spendin' many a night in me nightie, pushin' the dog through the dog flap to get it to go out, to train it, and it was very difficult. However the dog got to know me and at the time I had an electric wheelchair with a space underneath, so I used to take it down the town on the lead, and when I went into a supermarket, it would pop under this space, so I could take it round the supermarkets. Nobody

objected to it, I'm sure they wouldn't let me do it now but, this was in 1984. Then I used to have a bath nurse on a Monday and of course every bank holiday falls on a Monday, so when there was a bank holiday, I had no bath. And in order for them to catch up on the people that hadn't had a bath, it could be three weeks before I got the next bath, so it was, well it was just an absolutely awful time. It was one of the reasons why I had to have a hysterectomy, because I was gettin' at the time something like half an hour in the mornin' to get me up, and a call at night, and then a bath nurse once every Monday (if it wasn't bank holiday), and I had extremely heavy periods cos I'd got fibroids and I'd resisted, when I was married, havin' a hysterectomy because I feel that they do it too often on women. But around this time, one of my best friends left her husband, and she used to come on a Thursday night and I had got her dinner, and then we'd go out and then she'd stay overnight, and one particular night I think she must have got me up those occasions the next mornin' or something, I can't remember now, and it was just like a blood bath in the bed, and she said, 'You can't go on like this'. So it was really the failin' in the statutory services, to give me the right support that made me have the hysterectomy. So, I think it was in 1986, I went in to have this hysterectomy. I remember bein' put in a ward with lots of young people havin' abortions, and 'ow I found this extremely sad because I'd always wanted to have children and the fact that everybody was visited by their partner, and I got no visitors: well very few. The treatment I received was awful. When the other women in the ward were recuperatin', they were able to get up the next day, but nobody got me up. And in the end I complained about not bein' got up, nor did anybody wash me (because I couldn't have a bath). They didn't even bother to wash me till I asked them, and when I got somebody to bring my electric wheelchair, they sat me on a towel, and I remember this towel bein' bloodstained, and nobody botherin' about it. I mean the treatment I got was awful, and if I got up into the wheelchair, nobody would put me back on the bed for bed rest. I only stayed in the hospital six days, I couldn't stand it any longer, and I came home and I got no more support I think by this time. I was gettin' something like two hours in the morning and two hours in the afternoon, plus the district nurse assistin' me to get into my nightclothes to go to bed, and I 'ad to still haul me legs in and out of bed, even though I'd had this hysterectomy, where most women in those days were not to lift a kettle

up. I mean it has changed a bit since then, but it was quite bad. So, that brings me round to 1986.

*So looking back at that now, I mean, I wonder what you felt at the time, and I also wonder, how it is looking back at that experience in hospital particularly? How did you feel, because presumably it was partly because you were disabled that you weren't getting any help and assistance?*

I think it's the same now. I don't think nurses are taught how to nurse disabled people in hospitals at all, they don't understand the added skills that they need in order to make it right. They blame it on lack of staff but I don't think it's that and, you know, if you can't reach your drink, it's left on the locker. I don't think it's changed an awful lot really.

*And at the time, well you said you left early, after six days?*

I left after six days cos I couldn't stand it any longer. I thought I'd be better in my own home.

*Mm. And after your husband – I mean going back a bit on what you've just been talking about – after your husband left, you obviously made a number of ways of getting on with life. But I wonder how you felt also at the time? How, you know, did it feel being on your own, probably for the first time for a long time?*

Mm, it was very desperate really. I felt very lonely. But the first two years were a bit like, I should think, the first stages after a bereavement. I was so busy sortin' my life out, I think it hit me more after that because I'd got to sort out how I could get by each day really. You know, gettin' up in the mornin' and goin' to bed at night was an absolute major thing for me, as I'd never had to do it before because my husband was my main carer. And a lot of people 'ave asked me whether I think that was the cause of 'im leavin', but I don't think it was, because I did loads of things for him, it was a reciprocal process really, so I don't think that had anything to do with it. I think it's

just the same as any other couple, I mean, people do grow apart, and I do think that when 'e took up with the Open University, 'e'd always wanted to have an education and his mother 'ad put him off. He'd passed to go to the grammar school but she'd put 'im off – I think she wanted 'im to get into work so he'd be earnin' and I think that it sort of opened a lot of different things for 'im.

*I know you don't want to talk about this now but what about the OU for you? You know, when did you decide, and how did you decide you wanted to go in to do a degree? How did it start?*

Well it started when I was made redundant, and I didn't want to vegetate at home, so I decided to do Open University. And I decided to specialise in Psychology because I've always been very interested in what makes people tick. I don't think it taught me that at all but I'm still interested in it. And I did all the curriculum for belongin' to the British Psychological Society, I took all those modules, especially if they had a summer school attached to it because I loved goin' to summer school. I think I really wanted to be a full-time student. I'd never had the opportunity to go, and I saw this as my opportunity. I found it very difficult because I'd missed a lot of education, and at the time there were a lot of people doin' degrees who had just got their Diploma in Education, and if they got a degree it enhanced their salary, so my markin' was on a par with teachers who've had a lot of... So it wasn't easy. I always did very well on the tutor-marked assignments – I'd always get an A or a B, but I was hopeless at the exams, and I think it was because I'd never taken them before, and I just went to pieces, so that brought my mark down, but I always felt it made people take me more seriously. I don't know whether that was in my imagination or not, but I always felt if you could say that you'd got a degree, people did take you a little bit more seriously.

*I was just wonder... Ooh! What's happened there? [Laughs.] I was wondering how you got on at the OU with their attitudes towards disability, and what kind of provision they were able to make, in those days?*

Well I was very lucky in the fact that I paid the first year's fees, and then after that Leicester Education paid them for me, so I didn't have that to worry about. I found it very difficult after Brian left to get to the tutorials because I was reliant on somebody pickin' me up and takin' me. They allowed me... I did the exams at home with someone sittin' over me, and they allowed me some extra time, but I always felt that it was a bit of a false environment. And I remember on one occasion I used to have a cat, and the invigilator got up and tripped over the cat, so it wasn't very conducive to doin' exams. At summer school, I used to love summer school cos I really loved bein' with the other students, and you were able to bounce the ideas off them, which is one of the big negative things about bein' an OU student – you don't have the other people to bounce the ideas off, and you have to be very self-motivated because, you know, you've got to make sure you set the time and the date to do the studies. But at the Open University summer schools, although I was included, when it came to the living quarters, the accessible part of the college was never in the same buildin' as the other students, so I felt quite excluded from them in that respect. But I think, in their time, they were quite innovative in what they did, to support disabled students.

*And that helped you through that period when your husband left as well, perhaps?*

I'd one, two, no, four years when he left, and it took me six years to get the ordinary degree. And when 'e left I felt like givin' up to be honest with you, because I did go into a state of depression. But I thought, at the back of my mind, 'Oh I'm not gonna let him beat me, and if 'e gets his degree, I'm certainly goin' to get my mine.' So I went on and then I did Honours, so it took me eight years to get the whole thing because it's quite hard. I mean, when I was at work doin' it, that was even harder for the first year, but when I gave up work it was easier, if you could motivate yourself to do it, which after 'e went that was quite difficult. So yes, it took me eight years to get the Honours but I felt quite a deep satisfaction when I got it. Me mum and dad were alive at the time, and I remember they really spoilt the day, because I'd got a couple of friends to take me, I went to Birmingham Town Hall, and me mother she had to be the centre of attraction and because she wasn't she decided that she was goin' to be bilious on the way. But when we got there, decided to eat a whole load of sandwiches,

you know, and I never had an official photograph taken and I always regret that. And we had a meal in the evening with my parents and this couple that 'ad taken us, and I remember that wasn't a very pleasant experience and I'd always thought that my husband and I would be goin' up to collect the degree together, and of course he wasn't there so it was a bit of an anti-climax.

*And then, I guess it took some while to sort things out, sort your life out, and continue without him?*

Well, in 1991, I managed to get some fundin' from the Independent Livin' Fund, and in the beginnin' I used this to go out socially. I think I started on about 14 hours a week, and then one evening, when the district nurses came to get me ready for bed, I was entertaining two friends, and they seemed to be takin' an awfully long time to come in to the house. And when I went out the kitchen to look what was happenin', the particular nurse was donning a plastic pinnie and rubber gloves, so I said, 'Oh, what are you doin' that for?' and she said, 'Cross-contamination,' so I said, 'Well I've never known cerebral palsy be contagious,' and I was really annoyed about this. Anyway, it was one particular nurse who had it in for me, and I did report her to the hospital where she came from, and I got that actually stopped, but she was just carryin' out the rules to the letter, you know, and it wasn't necessary really. So that was my bit of fundin', and then I gradually built up the Independent Livin' fundin' to quite a lot of money, and then about the same time I wrote to the then Director of Social Services in Leicestershire. I'd been on a committee for Social Services and they'd asked me to go to the King's Fund in Leicester – I think they probably rue the day they ever did this – and I met there Jane Campbell, who was like the guru of Independent Livin', who was already buyin' in 'er own care. So I wrote to the Director of Social Services and said that, you know, what he was givin' me in the form of indirect services was rubbish, and that I wanted to swap the services of, like, the district nurse, the home carer, and the bath nurse for cash. And it took me two years to get him to see that, and then I managed to get 55 people in Leicestershire on it, and it was called The Independent Livin' Project [ILP]. It was called Indirect Payments because the cheque went to an organisation of disabled people in Leicester

City, Fair Deal, and then they used to just put the money into my bank account because you couldn't have money paid straight in from the local authority. I mean people had always been able to have their pensions paid in or their benefits, but not from the local authority, and this is when disabled people protested against this, and we all went to Parliament and tied ourselves to railings and things. And we managed to get a change in employment law – sorry, in the Social Security Act – so that local authorities were able to pay you directly into cash, but in many ways the Independent Living Project was far more liberating than direct payments, because there was very little accountability, and you just 'ad a form and you put the date, and everybody that worked for you 'ad to sign it, and then it was just sent back, so there wasn't the monitoring processes there are with direct payments. And then of course in 1996, I think it was, direct payments came into being, so the ILP then automatically changed into direct payments, so my fundin' is a mixture between the two. So from Brian... [Telephone rings. Break in recording.] So basically, for the first seven years, from when my husband left me in 1984 till 1991, it took me seven years to get any quality of life at all. And I started off with a very small package of care till I managed to get 24/7, but it wasn't through a lot, you know, it wasn't given to me lightly. There was a lot of shoutin' and knowin' what my rights were, and I was very proud to get these 55 people onto independent living project because nobody had heard of it at the time and then, as the years went on, I got the full fundin'. And I found that it was quite dangerous gettin' meself in and out of bed – I resisted for a long time havin' people sleeping over, because it's such a lack of privacy in your life. I think I resent it more than people who've probably never known what it is to be on their own, but havin' run a home myself, and never havin' anybody in to support me, I found this terrible lack of privacy was very difficult for me, so I resisted it. But I'd got to a point where I'd get up in the night to go to the toilet and I couldn't get back into bed, so you know, a friend of mine said, 'You know, you've really got to do'. So then I started to 'ave sleep-overs and I tried all different sorts of shift patterns – I used to have eight-till-fours and I'd 'ave a gap, and then, different things, but now I have people that work for me, 24 hours a day.

*And during this period, how would you describe your contact with disabled people? I mean is most of your time spent with other disabled people? Would you meet up with them, in different ways? Do you want to talk to me about that?*

Well I get onto a lot of committees, mostly to do with Social Services, and then we 'ad an organisation start in Leicestershire called Fair Deal, which was an advocacy empowerment organisation, and I became the chair of that. And then I became the chair of Leicester Centre for Independent Living so I was meetin' a lot of disabled people in a sort of, what I call, 'a work capacity', although it was unpaid work. But I didn't really mix an awful lot with disabled people on a social level: there were one or two people that I met on committees that I went out with socially but not an awful lot; excepting that in 1986, when I'd been on me own for two years, I must 'ave been talkin' to a social worker and they suggested that I went to Park House Hotel, in Sandringham. It's run by Leonard Cheshire, and I went there one Christmas. I went there three times in all and there I met a man with MS who I got friendly with, and 'e said would I go and stay with him when we got home. And I rang 'im up after this Christmas and said, 'What about me comin' over?' and I think it was quite a shock to 'im cos I don't think he thought I would. So 'e lived in Houghton Regis, and I went over there to stay with 'im for a weekend. [Pause.] So I went over to stay with 'im and in the beginnin' he used to send a taxi to pick me up and I thought it was really dead excitin' to be picked up in this taxi. And 'e lived in this flat that belonged to John Grooms, and I remember the first night because obviously I knew why I was there, and 'e asked me which side of the bed I'd like to sleep on. Right? So I said, 'Well I always sleep on the right but, you know, does it matter?' He said, 'Oh no, it doesn't matter'. So I remember that he'd got multiple sclerosis, I forgot to tell you that, and he was in a wheelchair, and 'e couldn't get in or out of bed because 'e got stuck, because it was obviously not the side of the bed that he usually gets into. So I had to get out of bed, in my wheelchair and motor into the lounge to call for the warden, and I remember bein' in the lounge and the warden comin' and I listened to 'im say to 'im, 'Oh Mike,' he said, 'I thought you said you didn't want to be disturbed because you'd got a young lady stayin' with you,' and he said, 'I have,' and I thought, 'Oh please don't let 'im come in the lounge,' cos there I am, starkers in my wheelchair. Anyway,

'e didn't and that was OK, and I did visit him quite a few times and then I arranged for 'im to come and stay here, and at the last minute 'e wouldn't come, and I was really annoyed, because it's always me havin' to go there. And I discovered that 'e'd got agrophobia and that he never went out of his house, I think he went out twice a year – once to the dentist and once to the opticians – and also 'e was really in the grateful mode to everythin' that was done to 'im which wasn't my scene at all. And I used to have to clean the kitchen when I got there because his home helps didn't do it properly, and yet 'e was rantin' on about how wonderful these home helps were, and you could tell that they were actually sort of soft-soapin' him and butterin' up and sayin' he was wonderful. And of course it went to 'is ego, and really they weren't doin' the job they were there for. And anyway, that lasted a little while, it did do my ego a lot of good because I thought that after my husband went that would be it and I'd never ever meet another man again. But I decided it just wasn't right because 'e wouldn't come out the house, basically.

*[Talking together.] And -*

She's a nuisance isn't she? Do you want to stop?

*Yes. Excuse me for -*

**[End of Tape 2 Side B]**

**Tape 3 Side A [Track 5]**

[Dog barking, interviewer talking at same time: inaudible.] That's a nuisance, them doin' that:

Well -

I don't know why they're doin' it. [Talking together: interviewer inaudible.]

*It'll be OK. And it's July 29<sup>th</sup> – I'm interviewing Anne Pridmore in her house in Market Harborough, and my name is Anne Austin. I think we've talked quite a bit about your earlier life, and I'm interested to find out a bit more about how you got into politics or into disability awareness, and how that's developed, and maybe something about the changes you've seen. OK?*

Mm hmm. I think my disability politics stemmed from when my ex-husband left me and I realised that the services just weren't there for disabled people. I think we spoke a bit about the bad services that I received and that I managed to swap the statutory services for cash, and it got me interested in how we could make changes so I joined a local advocacy and empowerment organisation in Leicester, and sat on the management committee, and then I became the chair. And then I moved on to Leicester Centre for Integrated Living and I stayed there for a year, and at the same time I got involved with British Council of Disabled People [BCODP], and I was a rep for them for about five years, and at that point I took on being the vice chair of BCODP. I then was asked by Rachel Hurst – a well-known figure in the disability movement, she has worked for Disability Awareness in Action for a very long time – to be a rep on the European National Council. From bein' a rep I then chaired that organisation for six years, up till a year last May. I went back to BCODP, havin' left it to be the chair of the UK Forum in October last year when they were lookin' for someone, and I took over in March as their acting chair, and that's where I am now.

*That's quite a lot of responsibility and taking on of issues. I wonder, in yourself, what do you feel, you know, has changed you and has developed [talking together] your awareness?*

Well the more I think about it, the more I realise that I've never really come out as a disabled person whilst I was married, because I think I was quite sheltered from what havin' a disability really meant, because I didn't use any services and I was just doin' the same as everybody else. But then, when he went and I realised that the services weren't there, I think that brought to light the fact that I was a disabled person, and what that really meant for the first time. And considerin' that I was actually 44 years of age and, you know, I'd always been disabled from birth, I think that's quite an interestin' point really.

*You know, I mean, do you remember any earlier experiences about feeling that your disability was important?*

I think I had very happy memories of bein' at school. I found the teenage years difficult when my peer group were gettin' boyfriends and I didn't, and then I felt very lonely. I found it quite difficult to get my first job after I'd been to business college, so I suppose in a way I did feel it to a certain extent, but when I got married, when I was 23, I didn't think about it a lot.

*I'm wondering whether you felt it was more important to be part of the 'normal community'.*

Definitely.

*Yes.*

Mm, sometimes I feel quite ashamed about that really.

*Now?*

Now.

*I wonder why?*

Because I think if things are not actually affectin' you, you tend not worry about them. It's like, I always think that if non-disabled people became our allies, we'd get a lot of changes quicker, but of course disability is something that non-disabled people cannot bear to face, it's in their unconscious, and it's one of their worst nightmares. I think they feel that if they don't think about it might not happen to them. I mean the facts are that the majority of disabled people have acquired impairments, rather than genetic or born with.

*And do you think that that distinction is important?*

The distinction between bein' born with an impairment, or... Ooh I think that's a big subject. Personally speakin', I don't think it does. I've got friends that have spinal injury for example, or become disabled in their adult life, and some of them have adapted to their impairment very well, and others haven't. And I remember, when I was studyin' philosophy and readin' Jean Paul Sartre, who said, 'It's not the disability that disables you: it's the attitude that you take to it.' I firmly believe in that.

*Mm. And was there a context of radical, political thinking in your home?*

Not at all, no.

*When you were a child?*

And certainly not as a child. I don't think any type of a politics featured very highly at all, and certainly not in my marriage. I mean, my ex-husband worked from him leaving college (when I met him) to his retirement last January at the Royal Society for the Blind – it's now called Vista, in Leicester – as an accountant, and he had

absolutely no politics at all. I never would have done the work I've done if I'd still been married to 'im.

*Mm, and religion: was that part of your background?*

Yes, we were encouraged to go to church and we went to Sunday School. I was a Sunday School teacher in my home town of Stockport, and when I came to Market Harborough I took up bein' a Sunday School teacher. It was quite difficult, because my mother-in-law was very much against it really, and made it as difficult as possible by always makin' sure that tea on a Sunday was quite late, or lunch, if I was doin' some mornin' stunt. Anyway I did persevere with it, and I kept teachin' Sunday School for some time, until the head of the Sunday School went away on holiday, and I took over while he was away, and basically the children liked better what I was doin', and there was a bit of an upheaval when he came back so I left then.

[Interviewer laughs.] Since that time, I think to be honest with you, when my marriage went wrong I lost a lot of faith in religion, and I don't go to church regularly, I do go now and again but I don't think it's because I've got any great faith, but I think the comforting thing about going to church is that it's something that always stays the same; in a changing world, the service is always the same, and I've found that quite comforting.

*But you don't feel it has much relationship to the kind of ideas and the work that you do now?*

No, not at all.

*That's a separate part.*

Mm.

*And so, I mean, obviously it was partly circumstances that made you to begin think and change your ideas, develop your ideas. Were there also any people who you would actually think were quite important in this process?*

Mm, definitely Jane Campbell, who we used to call... she was like the guru of the Independent Livin' world, who I met in London and I very much admired 'er. And at the time she'd made a video about employin' your own PAs [personal assistants], and I remember usin' it in the beginnin' as trainin' when I first started employin' people. Yes, I thought she was a great inspiration, and now I think she's chair of the Social Care Inspector of Excellence. She's got 'erself a very good job, she used to work at NCIL (National Centre for Independent Livin') and I think, yes, she was quite a role model for me.

*You've joined the organisations and you have been chair of a number of organisations – can you tell me a bit about, you know, being chair of an organisation, how you find that and what experiences... [Talking together: inaudible.]*

Well it's not an easy job. Like all committees, whether it's the gardening committee or a disability committee, I think there's the professional committee goers, and there's those that actually do some work, and that's the same whichever committee I've ever been on, and it's amazin' how these professional committee goers are very quick to shout you down if they think you've done something wrong. I think it's very difficult times for charities, whatever those are, to get good trustees nowadays, because the same old faces turn up at the same things. The only value you get out of it is by somebody tellin' you you're doin' a good job, and not many people do that, and I think in many ways it's a bit of a thankless task, and I think that that's why lots of organisations are findin' it difficult to get trustees and directors. I also think that, with the charity law as it stands, people don't realise what a responsible job it is and many organisations have not got any money to do trainin' with their trustees, which can be quite dangerous if the organisation gets into financial muddles or whatever. So, I just don't think it's easy for these organisations to find the right volunteers.

*And, you say it is a thankless job,*

Mm.

*I wonder what it gives to you personally – the involvement and also maybe leading, chairing?*

When the UK Forum actually collapsed last year, due to financial loss, I had about six, seven months without doin' anythin' and I soon declined. I have suffered on and off with depression for about 20 years, and I find that the thing for me is, it keeps my mind active. I mean I've got lots of hobbies I could do, which I say I've not got time to do them, but I do enjoy bein', 'specially the chair of an organisation, meetin' with government departments and tryin' to get the viewpoint of a lot of disabled people I find quite, I don't know whether the word's 'gratifying', but it gives me a certain buzz.

*And how are you finding this work you're doing in Europe still? Can you just remind me what...?*

Well although the UK Forum went down last May... sorry, last July it went down... they've started a new one now. It's a different title but it's the National Council because all European countries have to have a national council which belongs to the European Disability Forum – it's like an umbrella organisation. And I 'ave just been within the new committee, been elected again as the delegate to Europe on the Disabled Women's Committee. I've been doin' that for now about seven years; it began by us makin' a manifesto for disabled women and children, which was like a toolkit, and when I was part of the forum we used to have a women's committee in that as well, but we've decided now that we're not gonna have a women's committee in that but we're runnin' the women's committee through BCODEP (but at the moment it's only via email because we've got no money).

*And what do you think the value is? Can you just tell me a bit about the value of having, or maybe the relationship between disability and women's issues, as you find it?*

Well...

*Big topic. [Laughs.]*

Sorry?

*It's a big topic.*

Yes. Relationship, right. Well, there's over 51 percent of disabled people – there's more disabled women than disabled men – and in the new UN Convention on Human Rights [United Nations], our government doesn't want to make a particular issue with regard to disabled women, they want to mainstream it so that when they talk about 'disabled people' they are includin' disabled women. But I and a lot of my colleagues do not think that that's right, and we've been tryin' to lobby our UK government, which at the moment has the presidency in Europe to change this. But what they're sayin' is (well even the colleague of mine who goes to the UN Convention with the government, and I can see his point) that when you've got so many nations havin' to sign up to something that is so very complicated, you're never ever goin' to make them sign up to particular areas in the UN Convention that are about women: so that's one aspect of it. However, in the disabled committee in Europe that I'm in, we don't actually think that, and I've been supplyin' one of the ladies who's goin' to the UN Convention (who lives in Holland) with information about what our government thinks, and there's some lobbyin' goin' on at the moment about that. I do think the issues in all aspects of disability are different for women than there are for men. I mean, my particular interest is anything to do with independent livin', and I think that there are issues around how much fundin' disabled women get in comparison with disabled men. I think it's a lot easier, and this is just not my own thoughts, statistics have proved that disabled men can get more fundin' for everything, whether it's

personal care or child support, than women, because women are seen as to be the carers, whereas men are not. I think there's a lot of issues which, if I could get the time and the money to do this, I'd like to do a research piece on it, about employing personal assistants, the difference between doin' that when you're a disabled man and a disabled woman, because a lot of men are not that bothered about whether they get their house clean or what they have for tea, as long as they've got some nice bimbo on their arm, that somebody outside might mistake for their partner. So there's, you know, a lot of things about that. I think it's much more difficult for women to accept other women into their kitchens, especially when they've been used to doin' it from themselves. I don't think, I'm a bit generalisin' here but, many men are not so emotional, so they don't get so involved in the emotions of the people that work for them, which as a woman I think you do get more involved in it. And I've found that I've been employin' people now for 13 years, and you can't train a good PA, they're either born it or they're not, and I think the problem is that a lot of women, and possibly men, I have had male PAs come into this work because they're not cared for in their own lives, and it's a sort of catharsis, so they're transferrin' that onto the person. Now if you're a very independent person, and you only want your PA to act as your arms and legs but you do the thinkin', this causes problems, and I think that's where the trouble starts. If you've never known what real independence is, you know I've got a friend who lived with her mother till she was 47, and then she went into a young disabled person's unit for a small time while she got a flat: never ran a home for herself like I did and hasn't a clue about what independent livin' really means. So basically the people that work for 'er just run rings around her really, and it's quite frustratin' when you go out with her, when you can see what's happenin' but you can't do anything about it.

*I wonder whether... I've lost the thread of it. I wonder whether you feel that is, you know, the essential value of a PA – to be your arms and legs – or whether there is any benefit or anything to be gained by also using their brains. [Laughs.] I mean, I wonder what your feelings are about your carers?*

Well I think they have to use their brains, and if I inferred that I didn't think that, [interviewer laughs] that was a mistake on my part, because I think the job description is absolutely enormous: well at least mine is. And what they 'ave to do, I mean, in the real world you'd 'ave about three people doin' all those different jobs, you know, you'd 'ave a cook, a domestic, a chauffeur, an office administrator, but everybody that works for me 'as to 'ave some experience of a lot of different things. However, I do believe on workin' with people's strengths, and if some people are better at one thing than the other, for example I've got a couple of people who are very good cooks, I would manipulate my entertaining on a day when that person was there. The one lady, a very nice lady, but has no confidence in her own cookin' skills, I mean she can do it but she's very unconfident, I wouldn't dream of havin' a few people to dinner when she was workin', so I do believe that you can work on people's strengths.

*But I'm wondering how you think about your PAs. I mean OK you work to their strengths, I'm wondering what you think of them as individuals, or how their lives...? Or are they, when they're here, functionaries? I don't know.*

I think I know what you mean. Are they robots, or are they people?

*Mm, mm.*

Well, one of the questions that I always ask at an interview is: 'I don't want my PA to be my friend. Why do you think that is?' because sometimes people want to be your friend because they have very few friends of their own, for example, and also because PAs come and go. I think it's quite dangerous to get too friendly with the people that work for you. However the ones that have worked for me a long time and then leave for whatever reason, because p'raps they've got a back injury or whatever and they can't do the transfers, I've found that they've always kept in touch with me, which is quite nice, and we've probably developed more of a friendship when they've left. Obviously, I am friendly with them, and I listen to all their traumas and become their counsellors, but to me a good PA is somebody who can be a friend and companion, and you can have a bit of a laugh with them, but when you're outside of the home or

you've got friends in, then they become the professional, and they stay like a shadow in your life, and that's the bit that's quite difficult for people I think.

*I'm wondering whether that also is different for women and for men? Do you have any thoughts about that?*

I think it probably is, because I don't think men do get so emotionally attached to people like women do (unless of course they're hopin' to make a partner of their PA, which some men do succeed in doin' that) but mm, it's an interesting concept, one that I'd like to tease out in a research project. I think if you could [dog barking in background] do a research project on what makes a good PA, and why they stay with you, it would be of great value to lots of people who are actually lookin' for PAs now, have got the fundin', or are about to get their fundin'. I think it would be really good.

*Yes, because I mean the funding is becoming more easy to access and so on, isn't it? I mean it's the way that [talking together] the government want to goes.*

It's the way it's goin', mm.

*Yes, it wants us to go. I'm wondering also about, bad side, the abuse and so on, whether you have either any experience or do you have any thoughts about women (women particularly but perhaps disabled people) who have to deal with carers or people in their own home, who are abusing in a number of ways their generosity or whatever?*

I think it's an extremely interestin' subject and the abuse that's the most hardest to tease out or prove, if you like, is the mental abuse rather than the physical abuse. And I also think most people who are listenin' to this can see that I'm quite a confident person, and I've experienced this times in my own life. I've had theft a few times, mental abuse – which is just so difficult to describe – when you feel afraid of the person who's comin' on the next mornin' and how people can change when they're in your own home, but then you take them on holiday with you and they become

something quite different, and how difficult it is to get rid of people these days. I mean I was mentally abused by one of my PAs, and I sought support from my support organisation and told them that I was intendin' on gettin' rid of 'er and payin' 'er a month's in lieu of notice, because she hadn't actually done the job she was doin' for me then, less than 12 months. They said that was all right, so I did that, and then almost six months, she took me to tribunal. The first I knew was I got a letter, and what 'ad happened was that because I had a different system then, I used to have separate people for the sleep-over, and she used to do sleep-overs (and she was perfectly OK on that), and then someone left and it's always easier to employ somebody that you've got, which was a mistake because at the back of me mind I did think to meself, 'Will she be all right in the day?' but I took the easy way out, and seemingly, because she'd worked for me before on the sleep-over, this was supposedly an employment law called 'the continuation of contract'. So in actual fact she'd worked about 18 months for me, not less than a year, so she took me to the tribunal and I had to go without any legal help, because as an employer, even though on I'm income support, you can't get legal aid. And I mean you're sat in the waitin' room with all the other people who'd got solicitors, and then you have to go in, and I lost to the tune of £7,000. Now cos I know quite a bit about my rights, I sued, if you like, it's not quite the right word – took the support organisation to task – and they did pay for it on their indemnity insurance. But, to be honest with you, thinkin' back now, I wish I hadn't done that because they would 'ave only been able to take a few pounds off me a week, and she probably wouldn't have even got all the money, because I'd probably be dead before she'd got it, but I just wanted it over with and the stress of it (cos it went on for two years) and it took me back on to antidepressants and it was just a dreadful time. And the panel, I mean, you're up against a panel of people who've never met a disabled person before, they haven't got a clue what direct payments is and the very special type of relationship that you have with your PA, and tryin' to live, one of them referred to it as, 'Oh it's sort of like a marriage' you know, and I'm thinkin', 'No, it's nothin' like a marriage.' I mean funnily enough, we got such good vibes at the end of the summin' up. The woman in question had in court, well they'd told me before, one of my ex-PAs who'd left of 'er own accord because she didn't like the drivin', and when she left she wrote me a letter to say how much she'd

enjoyed workin' for me, that she'd learnt a lot, and if I'd got any shifts that didn't involve drivin' she would be prepared to do them. And I'd kept that letter, I produced that in court, but she testified against me, said I was a terrible employer, and they believed her.

*I'm wonderin', I mean how the situation can be improved, or what measures we can take to perhaps train disabled people to give them greater confidence, or to learn more about their rights, or [laughing] even non-disabled person to learn about what the situation is more.*

I don't think you've got any rights, to be honest with you. I think it's more the rights are on the side of the employee these days. But I think, I'm just about to join a committee at Chesterfield Law Centre that's lookin' into seein' whether we could join something where we were insured against this type of thing happening, so at least we could get good legal ad...

**[End of Tape 3 Side A]**

**Tape 3 Side B [Track 6]**

OK?

Mm.

OK?

In my contracts I have a six-month trial period, where if they don't think the job's what they thought it was, they can leave, and if I don't think that they're right for the job, then I can say, 'It's not working'. And that happened about 12 months ago with somebody who, well, the main thing was, it was a practical thing that she found doin' the standin' transfers difficult, so that was OK because I could say to 'er, 'Right.' We got somebody in to show 'er again, we gave 'er plenty of time to learn how to do it, and she really couldn't do it. There were lots of other issues but they were more airy fairy and difficult to prove, with that one that was a straightforward case, you're doin' the lift, it's part of the job, if you can't do it, then that's it. But where I think it's difficult is that I've got a lady that's started with me now, she's been with me a month, and I cannot relate to this woman at all, and I know that she's not the right person for me, and I am within my rights to say that within the six months, but it's very difficult to get rid of somebody in that respect because you don't relate to them, so I'm hopin', because she's made a few comments about a twinge in 'er shoulder, and I'm keepin' my fingers crossed that I can say, 'Well it's part of the job and if you can't do that,' rather than this intangible thing. But I think to me, I mean obviously doin' a lift is important, but bein' able to clean a house to me is not that important, you can always say, 'Well I'd rather you did it this way,' but to have the right relationship with the person that you're going to spend an awful lot of time with is absolutely crucial.

*I mean, in those respects, it is more like 'a marriage', isn't it?*

Mm, mm.

*It is a relationship. I'm wondering whether your attitude has changed, as you've been employing PAs for a while: whether, you know, you're more aware, I suppose, of some of the difficulties as well?*

I think I'm more clued up than I was when I started, I think I was so grateful to get away from Social Services, district nurses and carers, home helps and bath nurses, I think I would 'ave accepted anybody comin' in the house. But of course when you've got a lot of people lookin' at my life would probably think the crème de la crème, then you are lookin' for perfection I suppose, so yes, I think it has changed.

*Mm. And obviously having good carers is a important basis for your independence. I'm wondering in what other ways you feel that, you know, you've gained greater independence or become more aware?*

With respect to what?

*Well, I suppose I'm thinking of the issues you've taken up, the work you're doing, and so on. Because, you know, you sketch out for me a complete change when your husband goes, and then many people would say, 'Well that's a loss and you're probably lacking, you know, you probably would have lost out there.' But the way you seem to be telling it is, that actually your life has got much fuller and much more enjoyable or... [Talking together: inaudible.]*

Well it didn't [talking together] feel like that for the first two years.

*I'm sure, I'm sure.*

It was horrible. And if I, at the time, could have changed it back, I would 'ave done. But I realise now, and I did after about probably seven years, when I got some money to buy in my own support, that I could do a lot more things with my life than I would have done with my ex-husband. But of course you don't realise that at the time

because it seems quite rosy, but I would never have travelled all over Europe doin' the work I've done, and the other interests that I've taken up. I wouldn't have done them with Brian.

*So the basis of it really is the independence afforded by having carers who are, you know, helpful and useful?*

Definitely.

Yes.

Mm.

*We were beginning to talk a bit about Europe: what attitudes do you encounter there which perhaps are similar or not similar to your own?*

Well I have to say that in comparison with Europe, we're not doin' too bad here, but of course we don't tell the government that when we go to their meetin's. [Interviewer laughs.] But, for example, the Scandinavian countries that used to be ahead of us are not now, and to a certain extent... [Telephone rings. Break in recording.]

*Yeah, we were talking about European [talking together] attitudes and -*

Yeah, well as I was sayin', in Scandinavia you don't get 24 hour care fundin', unless you're on a life support scheme, and 15 hours is as much as you get. And in fact one of my colleagues on the disabled women's committee in Europe actually died two years ago because of that [sound of mobile phone in background] because she got pleurisy and there was nobody to help her in the night. (That's goin' on my mobile). And they certainly haven't got the independent livin' movement like we have, but surprisingly enough some of the eastern bloc countries, like Croatia, has got a very good independent livin' movement, and they've got direct payments and they've had it some years. I don't quite know how good it is, I've been dyin' to try to get meself

over there to speak on something, so that I can find out, but I haven't. So there's that side of it, the other side is that the eastern bloc countries haven't got the charities that we've got, which I think is a plus, because in this country we've got a lot of organisations for disabled people that get all the fundin'. I won't name them, but I'm sure you all know who I'm talkin' about. And you have to break down those barriers first before you can really empower disabled people. British Council of Disabled People is always very hard up for fundin' because the government are not goin' to fund an organisation which is really proactively campaignin' against the government, so I think that is one thing that they are in advance of us in the eastern bloc countries, but not in other European countries (I'm talkin' about the eastern bloc countries who've just joined Europe now). There's, for example in Spain, a very big charity, I can't remember the name of it at the minute but it's for blind people, and they get all their fundin' by sellin' raffle tickets on street corners, and it's always the blind people standin' out in all weathers, sellin' the tickets, when I know that it's non-disabled people who are in the offices, getting big wages. So charities do ruin a lot of countries.

*And you were talkin' about the churches and the non-disabled world. I mean, what's your strategy and your wish for them?*

Well, you could give a very good example at the moment of Scope that's tryin' to change it's image by eventually shutting down its residential homes, and its special schools. No one can deny that this is a major step forward, if they do it, but of course those are the things that bring them revenue. They are at last beginnin' to employ disabled people, and 'ave recently have jobs which have been specifically for disabled people, in their adverts, which is good. But I am keepin' quiet about how far they're likely to go, and I do feel that they're after the big one, and the government are thinkin' about makin' direct payments a national thing, rather than a local authority issue, and I do rather feel that Scope are waiting in the wings to take this on, and I'm not sure that that would be a good thing.

*Can you expand on the your reasons for - ? [Talking together: inaudible.]*

Well, they've got a new chief executive, and he's introduced several different committees, one of which is called The Ezone Think Tank (very new Labour), and he's got a lot of disabled people who are well-known in the movement, and I think that a lot of them 'ave been bought off by him, because obviously he needs people with expertise to lead his strategies, and I'm not sure that his strategies are goin' in the right direction. I am on the Think Tank but I go as an individual, I don't go representin' any organisation because it wouldn't be seen as very good for BCODP, because they are much against the four charities: they don't agree with charities that are not run by disabled people. But I always make that quite clear at every meetin', that I'm there to give my expertise just as an individual, but I'm not yet convinced of the strategies that they're takin' and whether they are really wantin' to empower disabled people.

*You said something about 'going the right way', is that what you mean?*

Mm but, you know, at the moment their trustees are not all disabled people in Scope. I can't remember the percentages now but they're not, and the majority of their workforce are non-disabled people, although 'e is employin' some disabled people. And in fact one of my friends has just joined 'im and had a lot of slaggin' off by disabled people's movement. My attitude is that if she can change their philosophy, then that's good, but it must be a very hard job for 'er to be there and try to change what's, I think, 50 years, is it, of history? And of course it's always been a parent-type organisation, that has been run, the smaller groups, by parents, you know, the local groups, so that's a lot of barriers to break down.

*You were talking I think earlier about training for trustees, and perhaps disabled people getting training, or getting greater expertise to be involved in such organisations. Can you tell me a bit more about that? You were involved in it or you were hoping to be involved in it?*

At BCODP we are havin' some trainin', it should be on 19<sup>th</sup> August, although some people are tryin' to delay it because not many people are goin' to go, and they're tryin' to, well one particular person is tryin' to say that it should be mandatory for all volunteers. Now the beauty of bein' a volunteer is that nothin' is mandatory: in my opinion, you know. I'm very committed to the volunteerin' work I do, but if I don't feel that well that day, I'm not gonna do it, or whatever, so I don't think you can make anything that's not paid, mandatory. I do think that it's good to have trainin' for trustees, with the rules from the Charities Commission. I think that gettin' people to actually go to the trainin' is quite difficult because some of the trustees are in work, and they've got to have time off work and they have to have time off work sometimes anyway for meetin's (although we do try to have meetin's on a Saturday), so it's all a very complex issue basically.

*And the aim is to sort of skill up disabled people in general?*

Yes, it is.

*Do you think there's any other ways in which we need to skill ourselves up?*

To be on committees, do you mean?

*Well, in any particular sphere for disabled people.*

I think that it would be quite beneficial for disabled people who are receiving direct payments or any other type of fundin' to employ PAs to go onto a training course, but only if that is done by disabled people who have experience of employin' PAs, not by other organisations, who in my opinion know very little about it. I think that if this was the case and that people were introduced to the social model of disability within their practice with their employees, and they learnt more about employment law, even though the support organisations are supposed to provide it, basically because the tenders appear to me to go to the cheapest people, they're gettin' more and more people on their books and they can't possibly supply the support or the information

that's needed. And in my own case, in Leicestershire, they seem to me to try to put the fear of God into new people on the scheme, it's not a supportive scheme, it's more about, 'Have a CRB check [Criminal Records Bureau], because if you don't this might happen,' it's, you know, very negative. So, yes, I think that would be a good skill for would-be PA employees and I think, goin' back to bein' trustees in charities, a lot of disabled people find that bein' a volunteer gives them the confidence then to go on to be employed in paid work, and I think that's also a step in the right direction.

*Yes, I mean, that's interesting because you got employment and kept employment and moved on very much through your own efforts. I mean, I'm wondering whether, to think about it more, there are steps we should take, or ways in which we should move, which enable disabled people to move into employment more easily or, you know, in more real ways, rather than just token ways?*

Mm hmm. Well I mean, when we get our new fundin' for BCODP for the membership services, we are goin' to have two volunteers, but that's come through a volunteerin' scheme, which they will manage them. Now that's an excellent way of givin' people first-hand experience of work, but the problem with that is that for charities that have little fundin', they haven't got the support in order to support the volunteer, because whilst they're doin' that, they're not gettin' on with their own job. I know that within BCODP we've just had to make somebody redundant cos we haven't got the money to pay them any more, and one person's had to take five hours less a week, so the thought of takin' on a volunteer without some extra support, we just couldn't do it.

*There ought to be ways though, shouldn't there, of people gaining experience?*

And especially as this is the Year of the Volunteer, I believe.

*[Laughing] Yes. If you look back, and look forward, I mean, which parts of your work do you find most satisfying, perhaps?*

Workin' on women's issues: belonging to the Disabled Women's Committee through BCOOP, although it is only on an email basis at the moment. Havin' the money that we had to start the website for disabled women, although it's still live, it's not bein' updated because the money's run out. It still comes under the name of the UK Forum, but there's been so much interest in that because there's a violence and abuse pack on it and, you know, people 'ave downloaded it and found it incredibly useful. You always find that when you're on a committee with disabled women, they're much more supportive. I find that it's very male dominated – other committees – and they're very quick to shout you down: men. [Interviewer laughs. Break in recording.] Well no... You'll start me off.

*So you've had experience since your husband left you: about 21 years?*

Mm hm.

*Yes, and you've had a very different life since then, a very active life, publicly. I'm wondering about your private life. I wonder if there's anything you want to talk about there?*

Well, I've had several relationships. Some of them have been positive, some of them have been negative. I've, until recently, not actively sought out men but they've sort of bumped into me a lot of the time through volunteerin', because you do get quite a lot of lonely people go into volunteerin'. And when I ran the Gateway Club for example, which is a leisure club for people with learnin' difficulties, I met someone there. I also had a relationship with one of my friend's PAs. The disabled guy asked me to spend a week with him in his apartment in Spain (I think he thought I was interested in him but I was only interested in his PA). And that I think was possibly the love of my life after Brian, but it went terribly wrong when he announced to me that 'e was gettin' married in three weeks, and had not told me anything about it. And we'd been on holiday together a lot and he'd got an 11 year old daughter, and he used to bring her, and I used to take her out because I'd never had any children, and it was one of my biggest disappointments, not to have any children. I used to really enjoy

these times. [Dog barking in background.] When he actually got married, I did keep in touch with the daughter for a little while, and funnily enough she said to me, 'My daddy was happier with you than with anybody else.' He'd been married three times by this time, and she said, 'He won't stay with her: she's already dancin' him off his feet already.' You know how honest children are, so that was quite sad. And then I had a relationship with a man who came to mend the video, and then I advertised in Scope at one stage and I had response from somebody, but we got on as friends, but it never went any further, and he still actually writes to me, and after he left me, I mean 'e did do me quite a good service cos he asked me if I'd ever thought of havin' my kitchen revamped when my husband went and I'd never thought about it, and I did. Funnily enough, I got it all done to wheelchair level and then I got PAs so I didn't need it, but I did get a bigger kitchen out of it. And then I applied to papers and things like that but nothin' very excitin' after the PA to my friends, but I've not been in any sort of relationship for five years because I just got fed up with it all. Anyway, after Christmas this year, I decided that I was gettin' far too work-orientated and I should get more fun in my life so I joined a datin' agency. It's a disabled datin' agency, and I've met somebody on that, and whilst some people wouldn't approve because this person is married, he's not really with his wife. They live together but it's platonic. I mean, people listenin' to this could say, 'Well he's just tellin' you that,' but to be honest with you, because I've lived on my own so long, I wouldn't want to live with a man now. It's bad enough livin' with PAs without livin' with a man. So at the moment this is suitin' me fine, it's just quite young – I've only known 'im since the end of May. It can be a quite a difficult, sustainin' a relationship when you've got 24 hour PAs, but I have to say that they've all been extremely good about it, and taken it on board. I don't quite know how I've done it but I've never really been short of a man in my life in the last 21 years, and I think I've been extremely lucky, and I do feel for disabled people that never make a relationship, and I think a lot of it can come from the fact that they've not got any self-confidence. I always say the one thing that my mother did for me, was that she gave me a lot of confidence, and I've always been of the opinion that I'm as good as anybody else if not better. This has sometimes served me in a negative way, because it feels a bit like I'm climbin' up this hill and I

keep gettin' pushed back down again, but I do put the credit on me mother for that, and I think it has helped me.

*Mm. And have any of these relationships been long-term, well, not semi-long-term, [talking together] of long duration?*

I suppose the longest one was two years, with Russell, and the others have been probably six to 12 months. But the last relationship I had, it was over... well, I'd been seein' 'im quite a long time before but he came for Christmas and told me 'e was goin' after three days and 'e stayed over the New Year and 'e was 'ere eight days and I'd 'ad quite enough of 'im, and that's when I realised that I couldn't live with anybody like that again.

*And the practical things more difficult aren't they, when you've got [laughing] 24 hour PAs there?*

Yes, it's not very easy,

*Yes.*

but I tend to send them home. But of course you've got to have the right man, because a lot of things around disability and the practicalities of it can be quite distasteful, I think, anyway. Some men can't take it on.

*And have you found that the people you've, I mean, some of them have come through disabled dating agencies so have some experience of disability. Have you had any relationships where your partner was not aware or not disabled, or not...*

Well,

*... aware, I suppose is the word?*

Apart from the first relationship that I spoke to you about when Brian had left me, with Mike, all my partners had been non-disabled men. I sometimes feel quite bad about this, because I think that that's not very PC [politically correct] of me, but it certainly makes the whole thing so much easier.

*[Laughing.] I don't think it has to be PC or not PC. But I mean, what about their awareness and their sensitivity?*

Well this particular man, I mean, Russell was the PA so he'd got all the awareness: you know, 'e'd been workin' as the PA to a disabled man. But the relationship that I'm in at the moment, he classes his wife as disabled. I personally don't think it is a disability, she's got Crohn's Disease and she's got a colostomy – this is one of the reasons that she's gone completely off any sort of physical relationship – but it's been goin' on a long time, I mean I'm not talkin' about a few years, I'm talkin' about 10 years. And also she's a recoverin' alcoholic, which, although that's worked for the alcoholism, she's just not, with him if you like. I think it's a marriage of convenience more than anything else. But his father had a stroke and ended up in a wheelchair, so I suppose he's had some experience of it, but I don't think it's quite the same, lookin' after your father as doin' some things for myself. I mean one of the big issues was goin' to the toilet, because I mean I can't have any quality of time with him, unless 'e can assist me onto the toilet. And one of my closest friends said to me, 'Now I want you to promise me, that the next time you see 'im that you will tackle the toilet situation,' because she said, 'If you can get that over with, then that's [it],' and she was so right, and it hasn't been an issue, but I don't know whether that's cos I've been fortunate with the person or not.

*Possibly it's to do with your sort of courage and talking about things, because I guess for many people the whole topic is just too overwhelmingly difficult. [Talking together.] I mean, I wonder -*

I suppose I'm quite a sort of in-your-face type of person, and the way I put it to 'im was I said, 'Look, you know we've got to get this issue sorted out; there's two ways

we can do this.' I said, 'I can get my PA to give you a demonstration,' although I must admit, I did think that could be quite embarrassin' for 'im, or I said, 'We can muddle through ourselves,' and that's what we did. [Both laughs.]

*I wonder how important it is to feel one has a partner, or to the public awareness of partnership, or how far it is very much the private relationship that is the important thing?*

I don't think the non-disabled public has any idea of the importance of a partnership for disabled people and I think most of them think we're a-sexual. [Interviewer laughs.] A friend of mine, not the ones I've just been talkin' about, was with her daughter's mother-in-law the other weekend, and she was tellin' me that she had been talkin' about me, and told 'er that... cos this particular lady, she is in 'er early seventies, and her husband died 12 months ago and she just met somebody as a platonic friend... and she was tellin' 'er that I'd met somebody, and I can't remember the context of it so it's goin' to sound really bad, but she told 'im that we were actually sleepin' together, and the woman said, 'Well how does she manage that?' and I honestly think that, yes this lady was in 'er seventies, but I think a lot of the general public they see us as something different, and as far as 'ow important it is. I think it is important for women to 'ave a sexual relationship, no more different than men.

*Yes, I mean, I was thinking that disabled people, particularly that so often are regarded as sex-less or...*

Mm.

[End of Tape 3 Side B]

**Tape 4 Side A [Track 7]**

*Anne Pridmore's house, in Market Harborough, and it's Tuesday 30<sup>th</sup> August.*

*[Laughs.] I'm having difficulty here: I think that's it. And I'm Anne Austin. [Laughs.] It's a while since we met, but I think there's some things to take further. Particularly I was wondering, just to go back a bit, about your later time in school and your memories of that. You've told me quite a bit about how it was when you were in junior school but perhaps friendships, people's reactions, how you got on...*

OK. I've thought quite a lot about education lately, because [clears throat] there's poor old Baroness Warnock, who's not done disabled people much good in my opinion, [she] has now decided that inclusive education is not the right thing for all disabled people, and I strongly believe that it is. However, I have to reflect on my schooling, and think about whether, as the only disabled child in the school, was I included? It's a very long time ago, and I can't really remember much about it, but I remember moving from the junior school to the secondary modern because, as I told you earlier on, that every time there was an exam I was in hospital, so I just didn't take any, I didn't do the 11-plus. And I only remember being excused from things that were like physical things, like PE [Physical Education]. I remember finding Science quite difficult, and something to do with Bunsen burners, [interviewer laughs] and them not letting me do it because I'd probably set fire to the whole school. But I can't say that I didn't feel included, now I think that's very interesting, because I was probably the only disabled child there, and why that was, I really don't know. I can't really remember any lasting friendships from school. I remember going on Friends United [Friends Reunited] and finding one person that was in my school [sound of wind chimes in background] that actually remembered me, which I thought was quite interesting, because as the only disabled person in the school I must 'ave stood out, I would have thought. My friend Adelina, who was my best friend, she was a good few years younger than me, so we didn't actually meet up much in school. Adelina lived across the road from me, where I lived at the time, and we spent lots of time playing, if you like, together, but once I left school at 14 I don't really remember an awful lot about her, excepting that when I got married, she lent me her headdress: I do

remember that. [Interviewer laughs.] But she didn't come to the wedding which is odd, I suppose, although thinking about it, lots of my friends didn't come cos it was quite a limited affair. I don't remember much about the decision from going from secondary school to business college at 14, I don't remember really being included in it, or whether there was much talk about it, it was just done, and I went: so whether I was included in the discussions around it, I don't know. I do remember going to this college on my three-wheeler bike, and no matter what the weather was I had to go on this bike, and [clock chiming in distance] it was interesting because my family did 'ave a car around this time, but I still 'ad to go on this bike. [Interviewer laughs.] I think it was something to do with exercise being good for me. And really, that's all I know about school that I can remember.

*Mm. Any impressions or memories of how staff treated you or reactions of other people at the time, or language that was used?*

I can't recollect it.

*No.*

I'm sure that if there'd been bad things about the staff I would 'ave remembered them, unless I put them out of my head. I mean, I remember a Maths teacher that clipped me round the head with a plimsoll [interviewer laughs] like everybody else, because I was hopeless at Maths and I was terrified of 'im, so I never learnt Maths because of that reason. [Wind chimes.] But I don't really remember them treating me any different than the other children.

*And how much contact did you have with other disabled people at that time?*

None at all. I didn't really have any contact with disabled people till 1984. [Talking together: inaudible.]

*And how do you feel about that? I mean -*

[Pause.] P'raps it was my loss, I don't know, because since I've been in contact with disabled people, I've made some good friends amongst the disabled community. But it just never was to be, because when I left school I went to business college that was for non-disabled, young adults and then straight away from being 15 I went into work and there were no disabled people in work, excepting me really. I suppose really I must 'ave stuck out, because I was mixing in a non-disabled world when many people around that time didn't. I'm not quite sure why that was. [Wind chimes.]

*Mm. And, and even in work? There were no other disabled people?*

No, there were no disabled people in work that I can remember, and I certainly didn't get any concessions. I mean my first job was in a big typing pool doing invoices, and I had to type just as many as everybody else. I didn't get any favours, if you like.

*And what about your perceptions of yourself as a disabled person at that time, or your feelings about it?*

I think that I didn't have any hang-ups about being disabled, but I don't think I really recognised it, because I was mixing in a non-disabled world. The only time that I felt excluded was when my friends began to get boyfriends and make relationships, and I was then left: that was quite a bad time for me really.

*How did you sort of cope with that?*

I don't know,

*Mm.*

is the simple answer. I had to put up with it I suppose.

*So you say your awareness grew when you deliberately mixed and became part of the disabled community when you were, in 1984...*

Mm.

*which was when your*

Husband left me.

*husband left you. And so that's, I mean you, you [were a] [laughing] well-grown adult by then, weren't you? You weren't a child any more.*

Mm.

*And so that was partly circumstances that encouraged that. Can you tell me a bit about the importance of that? And you said something about confidence, and talked about being an invisible citizen. [Wind chimes] I don't know whether that's part of your developing perception of yourself as part of a disabled group, [talking together] or... [Inaudible.]*

Well I think it was because that when I was a married person, I think whether you're disabled or not, as a woman, it's much easier to be accepted in a couple, I think. I don't know whether I'm wrong or not, but once you become a single person, lots of the things that I could do as a married person I couldn't do when I became single, because I didn't have the support and the back-up of any personal assistance or carers. And I think that was when I realised and I got started into politics in the disabled people's movement, that I realised that disabled people were getting such a bad deal in this country, and I started to become political when I didn't get the services that I needed myself.

*So it arose partly out of practical circumstances?*

Mm, yeah. I think probably it was like an enlightenment for me because I think the one thing me mother did do for me was she gave me a very good concept of self, as far as everything in life was concerned (except sexuality because that was never spoken of). But in 1984, when I sort of came out as a disabled person, I realised that the negative side of this, of treating me like a non-disabled child, was that I felt like this story of the philosopher when you're trying to climb this giant mountain, with a stone on your shoulders, and when you keep reaching the top, it keeps rolling back, because I'd got these very high ambitions and I realised that I wasn't ever going to [wind chimes] attain them. So I think that was the negative side of it, and I still think that's left with me now.

*So you had considerable confidence,*

[Talking together] Mm.

*self-confidence, but disappointment as well.*

Mm.

*Has that been?*

A lot of people say that I've got a good self-image about myself, and I can only think that that must have come from something to do with my mother's nurturing, but at the same time I do recognise that, given that I wasn't disabled, I probably wouldn't be sitting doing this now, [interviewer laughs] I'd be doing something quite different. And as far as my career's concerned, I think it was disappointing for me that I didn't attain my true ability in a career.

*Yes, we've talked a bit about St Loyes. Again it's about, perhaps, other people's attitudes, the reaction of people you met, public attitudes in Exeter when you went out, you know, to the pub. Can you remember anything [talking together] about those times?*

I suppose going to St Loyes when I was 21 was a revelation for me – it must 'ave been because it was the first time ever I'd seen so many disabled people in one setting. I didn't... The care and support there wasn't there, and mostly one relied upon the other students who were more able, and that could prove a nightmare because you couldn't get... the girls' dormitories, if you like, were down a very big hill and there never seemed anybody available to push you up this hill to breakfast and where you did your work, so you relied very much on the other students who were more able. I don't honestly remember anything about them having any form of care there, they must 'ave done but I don't remember it, because if you needed the toilet you simply went with somebody who was more able than yourself. The same with doing your washing: if you couldn't peg it out, then you relied on somebody else. I mean it was an awful system really, but at the same time, it was my first experience of being away from home, and that in itself was enlightening, as well as which, although I'd been to work, we got spending money there, and I felt better off there than I had been when I was at work, because I could spend it all on meself, [interviewer laughs] and your food and that and your lodgings were all paid for. That's it really.

*I mean, I wonder whether there was any sort of feeling of solidarity there, amongst disabled students?*

I don't remember there being any politics around disability there. It was more about survival. The food was absolutely awful, so people got food packs sent in, and you did what you'd got to do on whatever course you were on, and looked forward once a month to the annual dance that they had, where they opened it up to the whole of Exeter, whoever wanted to come. [Wind chimes.] And that was like the highlight of the month because you could stay up till 12 o'clock then, and that was really late then, in the sixties. It seems unbelievable now, [interviewer laughs] but that was how it was. I think St Loyes is still going actually, I don't know whether it's changed at all but it was quite archaic when I look back on it. But to me, I suppose in a way it was like liberation, having lived at home.

*And did the whole of Exeter come? I mean, was there some mixing?*

Well there was an Army camp at one end of the road and a Naval place there, [interviewer laughs] and so they got loads of boys then, whatever there, who came in. I mean thinking back on it now, it all seemed perfectly normal then, but thinking back on it, I'm just wondering why they did come there, because was it really that they wanted to make relationships with disabled people, especially women, or was it a bit of voyeurism, and was it all it seemed? I'm not sure about that, looking back, but that's probably because I've got my political head on now and I didn't have it then.

*[Laughs.] Do you remember anything about the attitudes there? The way you were treated or?*

Well I was very annoyed because (I think I might have touched on this before) I was originally assigned to do a comptometer course and I did it for six out of the three months I was supposed to be there, and they decided that it wasn't the right course for me because I wasn't using all my fingers. I kept up with everybody else. They decided that wasn't right, so they sent me home and I was devastated because I was actually going out with somebody from, well he'd been a student there, and I knew that when I went back that [wind chimes] 'e'd be going out with somebody else because that was 'ow it was. And I remember being at home and thinking, 'They'll never put me on another course.' And what sticks out in my memory about that was knitting this zip-up cardigan in Big Ben wool, with these awful seagulls flying over the back and knitting it in the three weeks I was at home, then they sent for me and I went onto the PAYE course, of book-keeping etc. [Traffic noise in background.]

*I think you mentioned that you like writing? Can you tell me a bit more about that?*

[Clears throat.] I've written lots of things for disability press, and I do enjoy writing and [dog barks] writing poems and articles. I think that probably I would 'ave gone into some form of journalism, given that I'd not been disabled or things had been more enlightened. I went on a writing course: [dog still barking] not last year, the year

before, with the Argon Trust, and it was very good. It was particularly good in as much as they allowed your PA [personal assistant] to go free, which is always a stumbling block for someone in my position, because if you've got to pay for two people it often stops you going, so that was really good. They didn't join in the course, but they were there to support your needs, if you like. I think that it was quite an enlightening experience for the other students, because I don't think they'd ever met many disabled people, certainly not one like myself. I went on writing stories for children. I was quite disappointed that one of the tutors was not in favour of my ideas at all because the idea I wanted to do was to write a story from my two dogs' perspective for children under five, and each story would bring in [wind chimes] some sort of disability element, but not in your face sort of thing, so it was gently woven into the story. But he didn't think it was at all appropriate, but then again, I don't know, perhaps 'e was right, I don't know. I very much enjoyed going and they were very good about the access because they'd got a lift up to the place that you went recreation at night, and they hadn't realised that because I'd got an electric wheelchair you have to have a manual to go in it, and within two days they'd hired a manual wheelchair for me. So I could really recommend anybody who's disabled who's got an interest in any form of writing, going on one of these courses. I think they're really good, and I got a bursary as well for myself, so that was even better.

*Mm. So most of the writing you have done is factual but you'd like to*

[Talking together] Mm.

*develop the fiction?*

I think there's very few stories for children, that bring in any element of disabled people whatsoever, and I'm a firm believer that if disabled people were mixed from an early age, we wouldn't be as discriminated against as we are at the moment because there's quite a big attitudinal problem along disability and non-disabled people I think.

*Have you wanted to write from an early age?*

I've always enjoyed writing, it was my best subject at school: English Literature, and putting an interpretation on something that you'd read. At home now, amongst my personal assistants, we have like a book... it's not a book club, but we often pass books onto each other, and it makes quite a good discussion point about the book we've read. For example we've just read a book called My Sister's Keeper. It's about a child that was born with kidney failure and lots of other things and how the parents had another child that was a right match for 'er and she became a donor. So that's been quite a talking point, and interesting to see that my difference in attitude between the non-disabled personal assistants and the way they view the story, because I often feel that my sister who was adopted, was adopted for the wrong reasons, and it wasn't really about having a baby for 'erself but more about having a sister to look after me when I got old, which of course hasn't worked out because we don't speak to each other. You can't put that onus on any child, I don't think.

*Can you tell me a bit more about that, and where you are with your sister? Well, I know that you had a separation from her, but tell me a bit more about how things went on after you and she got a bit older.*

Well, when my husband left me, I 'ad quite a lot of contact with her because at the time she was doing nights, and she used to ring me up cos she was bored, and then there was a really big gap for about nine years, and then over, about, I think it's nearly three years ago, I got a phone call at half past 10 at night. I didn't even recognise her, voice, and she said, 'It's Catherine,' and I didn't know who she was and then it finally dawned on me. She said, 'It's your sister,' and what she told me was – and it sort of supports the novel I've just described – that she's a manager of a big residential home for elderly people, lots of them have got dementia. And she'd been on a counselling course and anyone who's been on a counselling course, you have to be counselled yourself, and during this course it 'ad come out that she always felt very jealous of me as a child (there's 11 years' difference between us by the way), but she thought that she was getting much more attention. I mean some of the attention I was getting

wouldn't be relished by anybody, which was being trucked to physio or having different operations etc., but I suppose in a child's eyes, although I'd had all the operations thinking about it before she came along, and she also was jealous of my success, which I couldn't really understand that because she's reached her potential in 'er career, she seemingly likes the job she does, even though it can be stressful, but then so can any job. But this all came out in the counselling, and that year I went over to see 'er, about three times [sound of knocking in distance] (she lives in Manchester, which is quite a long way from here), and each time I went, I had to stay in a hotel because her place wasn't accessible. And then last July – not this one, the one before – that year I said to 'er, 'Look, I've been three times now, you'll 'ave to come and visit me, cos I'm not going again,' and she came over and it was a complete disaster. I mean I'd always thought that she'd got an alcohol problem, she drank an awful lot when I was there, and soon as she came in (she got to me about five o'clock) she'd drunk nearly a bottle of wine before we went out at seven o'clock. And we went to this restaurant where a friend of mine happens to be, and when we'd ate our meal, I asked my friend if we could go and sit with 'er, and by this time my sister was well and truly under the influence of alcohol. And my friend's a black woman, and I didn't know this at the time but she was [wind chimes] really racist towards 'er because at the time I was speaking to my friend's PA who seemed a bit out of it (they'd gone as friends actually, not in a working situation) and in the car coming home she said something like, 'I've got a bit of a problem with that friend of yours,' so I said, 'Oh 'ave you?' and I wasn't really interested because she'll probably never see 'er again, and she said that, 'Coming over here and using our National Health.' So of course that, you know, I just... And then she also asked 'er what was wrong with 'er, which we never say that sort of thing, and my friend said to 'er, 'Nothing, what's wrong with you?' which I thought was quite a good answer. [Interviewer laughs.] Anyway, the next day she stayed long enough to eat her dinner, she wouldn't eat any pudding, and went home, and I've never heard from her again since.

*This is how long?*

Twelve, 13 months ago. So whether or not, I mean I 'ave pondered on it, whether or not it was because she realised that she was drunk, although I don't think she's in touch with the amount of drink she takes, or whether she just thought we'd got nothing in common any more, I don't know. And of course it's now gone on 13 months, and I don't feel like picking the phone up to 'er cos I can't see anything to be gained by it.

*It's always been quite a difficult relationship has it, [talking together] or not?*

It was difficult when she was in 'er teens and I was still at home but that wasn't long because, she was 13 when I got married. And me mother didn't like leaving us alone because she used to say she wasn't gonna help me cos she, by that stage, could help me to the toilet and things, but she used to say she wasn't gonna do it. But she left home quite quickly because she went into nursing and stayed, you know, in a residents' place. I don't really remember it being that difficult when she was a baby, but when she got to be her teens it was quite difficult. [Break in recording.]

*I don't know whether you want to -*

Going back to the family dynamics, I suppose looking back on it, it was quite a complex family relationship. I mean when I was 11, in comes a baby, adopted, previous to that (I think it was two years before that) my mother got pregnant again, and the baby had cerebral palsy and died within four days, so then she decided they'd adopt a baby. I've always felt they didn't adopt that baby for the right reasons. It was to replace the baby that 'ad died, [wind chimes] to have a perfect baby, cos most people want a perfect baby, and to have someone to look after me when I got old. And probably my mother probably voiced that to my sister, I don't remember it but I wouldn't be at all surprised. It was a very complex situation. I was brought up in a family where things were not really talked about, and I've always found confrontation quite difficult myself and I think it stems from that. I'm very good at ignoring things, without having them out in the open. I find that's not been good for me with personal

assistants that work 'ere: I'm hopeless about confronting them about things that I don't think are right, and I think it all stems back from the way the family were.

*I'm wondering whether your mother ever talking about your disability, and her feelings about that. Cos it seems to me that she, if you like, worked very hard to give you a good life and so on and -*

She did, yeah. I don't ever remember 'er talking about my disability. In some respects I don't know whether she was in denial, and being in denial probably was quite a positive thing for me because she did work hard to get me included in things, like my education, going to the youth club, having friends in. I mean she was very good at letting my friends round when I was little, that sort of dwindled out when I got older because they wanted to do different things. But in a way, although it must have been hard work, I often think she probably wanted me for 'erself, and that's why the whole thing broke down, when I got engaged, I got married, because she didn't really want me to become independent, even though she'd given me the tools for independence by getting me to school and getting a job, etc. But when it came to moving away from Stockport to Market Harborough she wasn't happy about that at all, and when I left here, when my husband went, she was absolutely no use at all. I mean, she didn't involve me in looking for any other means in being able to stay in this house, the only thing she wanted me to do was go into [wind chimes] some residential home. It's very complex, I don't really understand it meself to be honest with you.

*And then there was the sister who was also supposed to be helping.*

Mm, and me sister...

**[End of Tape 4 Side A]**

**Tape 4 Side B [Track 8]**

OK.

Going back to my sister, she visited me twice in 20 years when I was married – one time was when she'd 'ad an argument with 'er husband and she arrived with two children, and the second time was en route to visit her blood mother, because she actually traced who 'er mother was. It must 'ave been really important to 'er, and I remember she asking me whether she should tell me mother she was going' to do it and I said, 'Well I wouldn't,' I advised 'er not to do it because [wind chimes] in my opinion there was no need to do it. But I found out a long time afterwards she did tell 'er, but it was a very negative experience for 'er because her blood mother 'ad married some eminent orthopaedic surgeon, and according to what she told my sister, couldn't have any more children, so they'd adopted an Eskimo boy. And it was all going quite well, I remember 'er buying 'er this jade bracelet and putting some money into 'er grandchild's account, until my sister paid an unannounced visit when she was having a party, and she hadn't told anybody, and then it went caput, really.

*One other area I'm wondering about is, and you may have covered this but, you got married really fairly early and you're a disabled: do you remember anything about (well you've told me how your mother felt, but) parental attitudes, and maybe other people's attitudes towards a young disabled woman getting married?*

Well it made the newspapers, so I suppose it was innovative in its time. Tragic but brave story. [Interviewer laughs.] My mother-in-law wasn't happy about it because she wanted to 'ave her son at home forever, and also I think, you know, his contribution to the board was quite valuable to 'er because she was divorced. But as far as other people were concerned, I think I was accepted really. I don't remember there being any aggro at all really.

*And when you moved to this house?*

Well, when I first came here in 1965, I did have a very nice neighbour, who used to bring me in from work every day, and well she was in 'er late seventies, because I live in old people's accommodation which I think is like a ghetto. And I came here at 23: I didn't fit in then and I don't fit in now, and I think it's very wrong that this is still going on today: you know, shove disabled people in accessible bungalows with old people, [it] is not the right way to go on. But since my husband went, I've had lots of trouble with the neighbours. Especially since I've had a full care package, because I think they see the people that come 'ere to work for me as my friends, or that I'm getting far more than anybody else and I don't deserve it. So, I don't have a lot to do with the neighbours, and they have tried their best to get me evicted by reporting me to the council for all sorts of things, but they've [laughing] not managed it yet.

*Yes, that sounds very un-neighbourly. [Laughs.] Your increasing involvement with disabled movement, I suppose after your marriage, but even perhaps locally before, you know, while you were married...*

Mm.

*... can you tell me how you became more aware of your own rights and so on? You've talked about that. I'm wondering how you became more involved with, maybe publicly or with groups in the town and so on, or within Leicestershire... [talking together: inaudible.]*

I never really had much to do with people in Market Harborough, in forms of disability clubs or committee meetings. I didn't really do much on that. I think for a small time I was on the access committee. I just mainly got involved with things in Leicester like Fair Deal and Leicester Centre for Integrated Living,

*[Talking together] Do you think -*

I did battle on that because I wasn't a yes-person, and the director wanted somebody who was going to say yes to all 'er different ideas. And in fact I don't think Leicester Centre for Integrated Living has done a lot for disabled people, meself. I think it's -

*Can you tell me a bit more about Fair Deal,*

[Talking together.] Yes.

*and your involvement in it?*

Fair Deal was a really good organisation in its time, when it first started. I'm afraid it's gone downhill now but it was the first organisation of its kind in the area, and it worked on empowering disabled people, and advocacy. And the first director, paid worker, was really good, but one thing that she did wrong in my opinion [wind chimes] was she left nothing for anyone else to take over, so when she went, it went. It's still there but it's not doing half the work that it was when I was on the management committee. And then I was chair for some time, but it's a bad thing really when one person is the organisation. You have to learn to redirect things to other people if you want an organisation to last.

*And so you moved from there and gradually became more involved in BCODP [British Council of Disabled People]. Would that be a natural follow-on, or what would you - ?*

I think I went to BCODP as the rep from Fair Deal, to start with.

*Can you tell me a bit about BCODP as an organisation,*

Mm hmm.

*and how it's changed perhaps?*

British Council of Disabled People basically works as a campaigning force for disabled people's rights. When I was first involved with it, [wind chimes] in the nineties, they were really vibrant and had lots of money to do things with, but unfortunately, in these latter years, unless you're what I call 'project bound' and you do projects, you can't get any money for core funding. And BCODP is definitely suffering from that at the moment, because the very essence of BCODP wasn't really about service provision: it was about supporting disabled people and the member groups, but finding money for that is impossible. So, what organisations like these have to do is to have projects and manage to put in some funding for management costs and do the campaigning work out of that, but it's not easy, it's becoming increasingly difficult. I think it's quite interesting that we certainly do have rivals in the big seven other organisations that get all the money, including Scope, and we've got an interesting scenario at the moment where Scope is trying to become more user-friendly, employing more disabled people and setting up different small committees. For an organisation like BCODP, this is quite difficult because it's [wind chimes] if you are on any of these committees, you seem to be sleeping with the enemy. I actually am acting chair of BCODP and I am on two of Scope's committees. I think that we should be involved with Scope, because if we don't sit round a table with them, they will do it anyway, and I don't see there's any difference between sitting on committees with Scope as there is between sitting with government committees, like the Department of Work and Pensions, who've been our enemies for years. But I always make it quite clear at Scope committees that I'm there as an individual, not representing BCODP. They've hand-picked a lot of disabled people to work with them, which has weakened some of the organisations that they were working with before, and I don't think they're finding it an easy ride at Scope either, from what I hear, from people who are now working there. You can't change an organisation overnight, and an organisation like Scope've been an organisation that's been run by parents for many years, and to hand that power over to people with cerebral palsy is going to be a difficult one for them. They are making some waves and I think they are committed to getting disabled people out of their residential care homes. I'm not so convinced that they are with us, the movement, in respect to inclusive education. I need to see more evidence of that. I'd also like them to rearrange the structures of

their committees. I'm talking about their trustees now, not their separate committees on Independent Living or the think tank or whatever, where it was the majority were disabled people, which they're not at the moment and the members had a real vote that actually meant something. Because I think that for the disabled people that are working there it's not easy, because they've particularly been invited to, I think, be like the flagship for Scope, and I think that must be an incredible hard thing to hang around on your shoulders because, as I say, it's not gonna change overnight. That's about it really.

*Can you tell me a bit more about the committees you are on in Scope?*

I first of all was invited to be on the think tank for Scope – which is a sort of New Labour phrase really, introduced by Tony Mainwaring, Chief Executive of Scope – where we all sit round a table and we talk about what should be happening for disabled people. One or two disabled people are doing very nice out of this, I think, and I don't really want to go into that. And then I'm also on the independent living zone meeting cos I'm very interested in any aspect to do with independent living. That's been quite good but it's gone into a bit of a moratorium at the moment for some reason, the last meeting was cancelled. [Wind chimes.] I'm trying to get Scope to take on a research project that I want to do, which is around researching what is this undefinable element that makes a good personal assistant, because I think that first of all I ought to explain that a personal assistant is the name that people who are in control give to their carers, and it's a very different job than being a carer because most carers come from agencies, and the person that's receiving the care is not their employer, which is what a personal assistant person is, although they can actually employ agencies. I don't know why people do that, but they do. So my idea is that if you could tease out what it is about this special person that is a good PA, it would 'ave a lot of benefits for disabled people in the future, because they would know what to tease out at interviews and how to get the best out of a PA, because I don't honestly think that you can make a good PA: they either are one, or they're not. And for me it's particularly around control, and I think that many people that go into the care profession are people who are not cared for in their own lives, and they want to

transfer it – it's a bit like a catharsis onto the person – and that's where I find a problem, because I don't want to be cared for, and I want to be the one that says what I want, and that's where I've always had trouble. And also you can have a really good PA and then something'll alter in their own lives and that has a spiralling affect on your life, so I think if we could do the research about, and also I think we need to build into it the difference between genders as well, because I think the relationships that women have with their PAs is different than men. I think they're looking for different things, quite frankly. So I think this'd be a really good piece of research. [Talking together] Well,

*Can you go a bit further into -*

a lot of men that employ PAs that I know, are more interested in having some bimbo pushing their wheelchair, [interviewer laughs] than whether or not they're a good PA, because it gives them credibility in the outside world, because most people think that when you're out with your PA, you're either in a relationship if it's that way, or they're your mother or your sister. I mean I must 'ave been mother to 13 different PAs now of every colour, that I must 'ave 'ad a very interesting life: [interviewer laughs] because that's the way the general public, they find that more comfortable because they can't see disabled people being in the driving seat and being employers. That makes it more comfortable for them. [Traffic noise in background.] But I definitely think, going back to the men and their PAs, it's not just about the sexual imagery, I don't think it's as difficult for a man giving over his kitchen to a woman because he's probably never been in the kitchen before anyway. And I think that's quite difficult for women because they know how they want things done, and they want to be in control of that, whereas as long as... I mean I am generalising so don't get me wrong I know there's men that don't, but on the whole men are only interested in getting their dinner on a plate in front of them. How it gets there, it's not very important to them. So, yes I think there are a lot of differences around [talking together] PAs.

*You have your own experience: have you had any comments or any evidence or examples from the general public's attitude to this kind of situation, where it's the PA who seems to be in charge?*

Yes, I often go out when people address my PA and fortunately, they will say, 'Well don't talk to me, talk to my boss,' and then that sort of throws the person who's asking the question. I did employ two male PAs the same time, that was quite interesting, they couldn't quite get their head round that, the general public. Mm, I think it's a very complex relationship, the relationship between a PA and the PA employer, and it's something that is quite difficult. I mean, I went to a wedding the weekend before last, and my PA sat more or less at the corner all night, didn't get involved. That's what I like, but it's not easy, either for you to see that happening because at the end of the day you do feel a bit guilty, or for them to take that back stance. And some people can't do it, and it doesn't need me to say that I'm not friendly with my PAs – I'm friendly with all my PAs, and I'm probably agony aunt to all of them. But what I want is a PA that knows when it's the time for us to have a bit of a laugh and a giggle, and when they know to go in professional mode. [Music in background: mobile phone.] And that to me is most important, especially as I go to lots of conferences and meetings: I don't want them involved. I've just employed somebody new, and I 'ad to 'ave a word with them because they'd got a file in their hand as we were going out and I was saying, 'Oh what's that?' and they said, 'Oh well this is all about NCIL, National Council for Independent Living. I wish I'd seen this before I come in, I could read all about it, read all up.' I said, 'Well what would you want that for?' So she said 'Cos I'd know more about it.' I said, 'Your role is to support me in my day-to-day needs, it's not about learning what NCIL does, that's my job.' And I think a lot of people think they're gonna score a lot of brownie points by getting into the disability issues, and to me that doesn't... I don't want them involved in that. It'd be like somebody who did his job as a motor mechanic, and took somebody with them, looking over the shoulder all the time: that's not what I want, that's my role. Their role is to support me.

*You've obviously, you know, had a lot of experience of carers and PAs and developing that, and you've obviously got quite an interest in that from your own experience. I'm wondering a bit more about, I mean you're on the Leicester Centre for Independent Living: can you tell me a bit more about your involvement there?*

I'm not on that any more.

*Aren't you?*

No.

*[Talking together] That was the past is it?*

I had years ago.

*Years ago. [Laughs.]*

Years ago, yes – when I fell out with the director. But I ran a peer support group for two and a half years, which I did actually get the money from Scope to do that, and it was really good. I organised the meeting once a month for other PA users, which, it didn't matter where they got the funding from, they could 'ave ILF [Independent Living Funds], or a direct payment, or it could be: what do you call it? Not compensation, but when someone has an accident type of thing – so it didn't matter the criteria. And it was, we called it Peer Point and it was a peer support organisation. I also got training in it, although that was a bit of a disaster because ACAS [Advisory Conciliation and Arbitration Service] 'ave got absolutely not a clue about the difference between being an employer in a large business and doing this. But it was quite good – it never grew to large numbers, but while it lasted it was quite interesting, and I think it was of value to other people who would have some sort of problem that they could talk together about the problems and share [sound of door closing] with other people who were employing PAs, and often, to even just know that another person had that type of problem, was quite empowering for them.

*So this [was] mostly a discussion group and informal?*

We did lots of [traffic noise in background] work on... We got training on assertiveness, being a good boss, that type of thing. [Siren in background.] We never really went down the road of employment law because it's a bit too tricky and I wouldn't want to advise anybody on that, being had on that score meself once. But just to actually be able... We had a telephone help line as well so they could ring me up, [traffic noise] if they were in difficulties, and I think just having somebody at the end of the phone to talk to was quite good.

*And the other side of it of course is being a woman, and you've had quite a lot of experience of involvement in*

[Talking together.] Mm hmm.

*disabled women's issues and all the -*

That really came about through being the chair of the UK Forum,

*Right.*

and because the UK Forum are members of the European Disability Forum which is based in Europe. The idea is to shadow the committees that they have on the European Disability Forum. It's a bit complicated,

[Talking together.] *Yes.*

but if you look at it like BCOOP (British Council of Disabled People) is like an umbrella organisation to many different organisations, like spinal injuries, that sort of thing: well the European Disability Forum is the umbrella organisations to all the national councils in Europe, so it works in the same way but to European level, not a

national level. And one of the committees they had was Disabled Women's Committee, [sound of siren in background] so I set one up in this country under the UK Forum, and then I used to go to the meetings in Europe, and about six years ago 12 women, from 12 different European countries, produced a Disabled Women's and Girls' Manifesto, [siren gets louder] and we used this as a tool in our own country. Because women's issues don't get a lot of funding in media, the last time we met was October. Whether we're gonna get a meeting this year I don't know. And we were trying to bring the manifesto into a more user-friendly document because it's quite large, but trying to work from a distance is not that easy, and it hasn't happened. And one of the leading lights – Lydia [ph] – has had quite a lot of illness over the last 12 months, so although we're on an e-group and we correspond about women's issues, we haven't actually met [more sirens] since last October.

*And do you find there are very different issues or perceptions within the EU, within different countries, or*

[Talking together.] Well,

*even different experiences of member countries' provision?*

Well in the UN Convention on Human Rights, which our government has been over to the UN on what's called an 'ad hoc committee', several members of our women's committee feel that in the document (the UN Convention) women should be [sirens still going] specifically talked about – disabled women rather than disabled people – because they feel there are things about being disabled and a woman, that are quite different than being a disabled man, and it's a double discrimination. But our government won't put that in, and because there's a UN Convention when it's in international level and there's so many people contributing, to get them to agree on anything [interviewer laughs] is taking years. So, I personally don't think that they're gonna win on that one, to make disabled women a particular issue. But definitely, I do think there are particular issues for women that there aren't for disabled men.

*Are there different issues in different countries, do you think?*

I think it's universal, the issues, whatever country it is, yes. [Chair creaking. Break in recording.]

*[Chair creaking.] OK. You were saying, you follow the social model of disability. Perhaps you could explain that a bit further, could you?*

Well I only got introduced to the social model of disability when I became a single person fighting for rights, through the disabled people's movement, and I think that it's been a good thing for me because, having spent the first 11 years of my life undergoing medical procedures to make me fit in, [wind chimes] to the world, and then to be told, 'That's not the right way to go about it Anne: the world should be made accessible so that you fit into the world'. The social model is not about the individual changing, it's about the world and the environment and the structures, both financial and physical barriers, changing to meet disabled people's needs. And I feel very strongly that if disabled people were introduced to the social model a lot earlier, that they would feel a lot more empowered, because they'd realise that it wasn't up to them as an individual to change. You know a very good example of this came on the television the other week, when they did that three-part story about disabled children's lives up to five [clears throat] (excuse me). And they had [coughs] this young lad with restricted growth on, whose parents were contemplating whether to have his lengths lengthened by so many centimetres, which is an extremely painful procedure. And, you know, it's unnecessary if houses are built with plugs [wind chimes] at waist level which he'd be able to reach, and light sockets etc., etc., so why should disabled people go through these awful procedures? And I think that a lot of newspapers talk about people being 'wheelchair-bound', which really annoys me because my wheelchair is my freedom. In social model terms, it's the same situation as buying a car: a car gets you from A to B, so why struggle? And often through a great deal of pain for people with a physical disability trying to walk around all their life, which is what I did, when it would be much easier and more comfortable and empowering, to sit in a wheelchair. I mean this is not just about physical impairments, it's about all sorts of

impairments, whether you've got a visual impairment, or hearing impairment, or people with learning difficulties – if the environment's made accessible to them, then they can be a member of society instead of being excluded. I also think that as a right, disabled people should receive all material in their chosen accessible format: whether that's Braille or tape or large print or pictorial form or whatever, because a large majority – 10.1 million – disabled people in this country don't know of their rights, because either it's not in the required format, or...

**[End of recording]**