

Chapter 3

I don't think I'll ever give up till I die

Rene Harris

Rene Harris, 1919–2000

I met Rene in 1991 in the course of my PhD research. I'd been pointed towards her by a contact in Luton who said she was the person to help me reconstruct the history of services for people with learning difficulties in Bedfordshire, and that she knew everyone. I formally interviewed her twice, to gather oral history data for my research, but we became friends, and I visited her in her home in Sharpenhoe on a number of occasions subsequently, each time gleaning more information. She was immensely generous with her time, memories, her store of historical treasures, and her contacts. If I can point to one person who made my PhD possible, and who brought my enduring interest in the history of learning disability to life, it was Rene. To me, she typifies the redoubtable energy and determination of the founder members of Mencap, 'the Society'.

I last saw her a few weeks before her death in March 2000.

This account is drawn from her own words, recorded at our interviews.

Jan Walmsley

Colin – how it started

Colin was born in 1941. I didn't know he was backward until he was three years old. He was admitted to hospital for medical tests. During that visit, the sister said to me, "He's very backward, isn't he?" That was the first I knew there might be something wrong. I was referred to a paediatrician who told me, in effect, to stop protecting him and put him down to walk. By the time he was five it was clear to me that he would not cope with school. They sent the attendance officer round, though it should have been clear to them that I'm not the sort to keep my children off school for no reason. My first son had an excellent record of attendance.

I had to look round for alternatives. There was very little. I was told by a friend about Osborne Road School. I said, "But that's the 'silly school'." My friend took me to show me around. It was in an old farmhouse with four rooms. There was no special transport, but the caretaker came on an ordinary

service bus to collect the children from the Town Hall. Colin went there for two years, but he wasn't happy. At Osborne Road they were supposed to be getting the rudiments of the three Rs into them, and he just couldn't cope with that. He left after I received a letter from the education authorities telling me he was 'ineducable' and should be excluded from school. I still have that very hurtful letter. Ineducable. It's a terrible blow. I tried to fight it but I knew I didn't have a leg to stand on. I knew he was terribly backward.

I was confused. I was indignant, I suppose. How dare they say my child was ineducable? And yet basically, I knew, though I did try to take it further. I had discussions with my MP, I had discussions with the Education Department in Luton, and they said, "Well, you have this avenue of appeal", and I said to my husband, "I don't think we have grounds for appeal." But nobody said what could be done, you see.

I was at a very low ebb then, and I opened my heart to a woman I met on a park bench. She said to me, "Well, there is another place, I don't know where it is, but I know there is another place because the coach comes round and picks up those poor little souls." That was how I heard about the Occupation Centre, in a lovely old house in Church Street – all been swept away now by the Arndale Centre – and in the garden was the most wonderful walnut tree. It was the first time I'd ever seen a walnut tree. The lady who was there, a very, very kind secretary, did all the work of the Department. It amazes me now when I go into Bedford House and see all these social workers, and then there are more at Dunstable. But this lady had it all on her shoulders. My experience with her was very kind. She told me about the Occupation Centre, and we went there. Colin went there, and he was a lot happier.

I went to Hitchin to hear Judy Fryd after I read about her in the paper. The first that I knew of her they had an article, '40,000 lame chicks', in the *Sunday People*. That was the headline, and I thought, "These children are like mine." Wonderful woman. I was absolutely inspired by her. Oh, I was so moved because she said everything that was in my mind. She said everything in her talks and in her groups that was in my heart and that I hadn't been able to say.

You see, you don't think it happens to anyone else. It wasn't uncommon, before there was so much publicity, for people to hide the fact they'd got a handicapped child. The only other people I knew were Mr and Mrs A. who were very friendly with my sister-in-law, and they had a Down's boy, Stephen. He never went out except in a car, nobody knew of his existence, and the neighbours used to say, "That little boy, he's like a monkey", because they used to see him looking out of the window for Daddy coming home.

It was the woman at Church Street who helped me form the Society, really, because she couldn't reveal any names because of confidentiality.

We had actually started the Society in 1955, and the way we did it was, we wrote invitations to a party in the old St Mary's Hall in Church Street and gave them to her, and she passed them on to people. I'll never forget that first party because I didn't know anything about mentally handicapped people except my own, but I was very good at catering. And all these people came, children of all ages, and they were very amused because, as they said, "How did you know about us, how did you know?" Well, we didn't, you see, and that was how our membership started.

We had lots of battles. When they opened the Dunstable Occupation Centre they wanted to make it small, they said they couldn't provide for a nebulous group, not knowing how many there were going to be. So we produced the facts, lots of people we knew about and they'd never heard about, and so we got a reasonably sized Centre, but within six months they'd had to take back their site at Kirby Road and start the adult workshop.

In and out of Bromham Hospital

"Put him away and forget all about him" – that used to be the advice – "Put him away and have another child." It's taken me years to persuade parents that it's not 'putting away'; it's 'letting go'. I had the decision forced on me, really, by my other children because I had a son doing A levels and a daughter doing O levels and this very disruptive element in the middle which you just couldn't cope with, and I realised it was either him or me, one of us would have to go away. I actually did go away, to a convalescent home in Brighton by the race-course to think it out – because I had a total breakdown. I spent days walking the hills out at the back of Brighton, and I realised things weren't going to be any different when I came back so I had to sit on my hands and take a fresh hold of the dear old soul, and pull myself out of it, and cope. And I think that was when I decided we'd have to. And this was the time when the first surge out of hospitals was taking place. There were such a lot of people – I'm sure it was the same all over the country – a lot of people that had been there for years, and only because of some sort of misdemeanour. They did go out to work, they went out of the hospital to work, so it was obvious they could go out and live a life in the community. Some actually married and came back to the hospital to show the staff their babies. And so there were vacancies in Bromham Hospital then, and this was the time I was at my lowest ebb. Colin was then under the mental welfare officer, probably Mr. French, and he said, "Well, there is a vacancy", and I thought, "Well, I'll have to take it." And the staff there – he hadn't been there very long – said, "We should have had him years ago. You've spoilt him." It was probably true. He did settle down very well – I was quite surprised really.

It is a very, very hard decision. I should think for 18 months after that I cried myself to sleep. I felt like a murderess. I really felt I'd condemned him to death. And that was when I threw myself into Mencap, heart and soul. I thought, "I must fight for all those who are in the community because perhaps parents won't have to undergo this trauma in the future if we can improve services in the community." There really were not many alternatives, you know. There was no adult training centre. I think I told you this before, that he was at Kirby Road, and there he was, this great six-foot boy. Mrs Bewes used to let him do all the humping of the furniture you know, he used to do all the moving of tables and chairs, things like that. But there was a party at St Mary's Hall, and all these little ones came to it, and I realised there was never going to be room in that school if great big boys, six feet tall, were occupying all the places, and Colin was one of them.

Throughout the 1950s and 1960s, the one fear of my parents was that their child would have to go to Bromham – they couldn't bear the thought of it. I tried hard to persuade them that it wasn't a fearful place; it was quite marvellous in those days. It perhaps wasn't ideal because they had those huge dormitories, but the surroundings were so lovely, and the staff were wonderful, really dedicated caring people, lovely people. You had your upsets, for example, clothes going missing and the fact they didn't want them to have their own clothes; they wanted them to have hospital issue, which was pretty awful. I used to keep a spare set of clothes for him. And there was the other upset: the masturbation by some used to upset mine, who knew it was not nice. So it wasn't ideal; but it wasn't as dreadful as most of my parents regarded it. I visited him twice a week, Thursdays and Saturdays. We had to get our own transport then. Before that we used to cycle, because if you went by public service it took all day. I knew a wonderful little lady from Hatfield, a Catholic – she used to go to Mass at seven or eight, and then straight on to public transport to get to Bromham.

When we parted with Colin, when he went to Bromham, I thought that was it; that was the end. I was absolutely amazed when we got back from holiday one Christmas and Mr Marsden, the mental welfare officer, was waiting to ask me if I would agree to him coming out of Bromham to be one of the first residents at Wauluds Hostel when it opened. I was absolutely amazed, because I'd been given to believe that they had to go about in the community and care for themselves, and I didn't think he could do that because of his lack of speech and he hasn't got a lot of confidence to go out. Anyway, I was very pleased, because he improved beyond belief when he came out; he was very much more aware and was making himself understood.

People

I doubt if Brian remembers his father. His mother is a dear little soul. In her garden a weed doesn't grow. She's very, very nice but she's practically illiterate. If she gets a form, she panics; she's on the phone, saying, "I've had this letter; can you come?" But what I'm sorry about is, I've known him since he was about eight. I suppose the Society took him on the first holiday. I think I told you about Mrs Messenger being the first home teacher in the county, and she realised what a terrible waste of time it was going from one end of the county in her car, just for an hour here, then driving back across the county, so she started groups, you see, and the first one was in Barton in the village hall. Brian never went to school because they wouldn't have him at Barton because he wasn't clean and he had tantrums. So, because his mother didn't have enough about her to find out what she could do, he didn't do anything until Mrs Messenger came on the scene. I'm so sorry about Brian because I did hear about him through Muriel Messenger, but I didn't really realise – I was so busy with everything else, and I didn't realise that his mother didn't have enough up there to become a member, and therefore she wasn't on my list. She didn't get letters or, if she did, she couldn't read them, and so she slipped through the net. At the time she would definitely have got attendance allowance, and related benefits, but she didn't have the savvy to apply and I didn't realise she hadn't applied. When we did, of course, it was too late; they'd started tightening up on things, not giving them as freely as they earlier did.

He's now got a job at Homebase. One of the reasons parents are afraid to let them go into full-time work is the fact that if they do not make the grade and people sack them you've got to go through all the channels again to get it back. I mean he would be earning £100 a week if he worked there full time, which is far more than his benefit.

I wouldn't say there were many middle-class children, not very many; the majority were from feeble-minded parents. I knew quite a lot of middle-class people who would not let their children go, even when the new centres opened. I know that Mr Marsden – who was at that time the Chief Mental Welfare Officer in Luton, and before that he was one of Mr French's boys from Bedford – he went to several of these people personally and told them that the Centre was open. They said, "He couldn't get on that coach with them", and one wonders what's going to happen. I mean some of these parents are now in their eighties, and the child is at home, a middle-aged man or woman. And I know that the parents' prayer is that their children will die before them – they definitely have this deathwish, and several of them are so poorly themselves, they are only hanging on because the child is alive.

There's a very lower-class family up the road here. Kathleen has Down's Syndrome and was one of Mrs Messenger's group at Barton – she was a

contemporary of Brian's. There are two sons at home who are very peculiar. There's another son who is married and who has turns, and there's Kathleen, the youngest, and then there's Dorothy – well Dorothy's unbelievable. She looks like a witch; she is absolutely filthy, her teeth are black, like black tombstones, and she sits by the roadside all day long. She has a bicycle and now she's developed a pram, but she has had a bicycle all these years, which she never rides, but pushes into Barton and back, and on the handlebars are six plastic bags – no one knows what's in them. Absolutely terrible; but will they part with Kathleen? No, she is at home with them all the time.

Opinions

I really do think our children need a family atmosphere, a mum and dad. That's why I quite like what Roy and Ann are doing. They are private homeowners and they are keeping the home small and as a family unit. Though I think Ann has got to learn that when you've got a family of five or six children they do not always agree. Of course, Ann hasn't got any children herself. I don't know if she's got brothers and sisters, but not having children she probably doesn't realise that life isn't always sunny. The authorities wanted Colin to go to Ann and Roy. I said no. The long and short of it is I am against private care. Nothing against Roy and Ann; they are doing a splendid job there, but personally I don't think it should be done for private profit. It ought to be done by the state. And the smaller the group the more difficult, because they can't get away from each other, whereas if they are in a house with 20 others they can go and join another group.

I liked Wauluds Hostel very much when Mr and Mrs Hills were in charge, with Mr and Mrs Bond as deputies. Mother and father. Then Mr and Mrs Bond moved on to open a home in Dunstable, and the Hills retired. That was it. No more joint appointments. I'm still in touch with them. Wonderful couple. They remembered every one of their residents, they remembered their little peculiarities, they remembered their relatives. Now there are so many workers at Wauluds doing part time and shifts ...

I don't think the younger parents are the same at all because we did so much spadework. There has been so much publicity through the media that they know at once as soon as the child is born whether it's a Down's or a spastic. They know immediately that they can get help, and they go all out for it, their children go into respite care from the word go, and they get all the allowances. They get the allowances now before the age of two. I always thought it was ridiculous to pay them Attendance Allowance at the age of two, because a child of two is a child of two.

I've been going through these Mencap *Yearbooks*, and it's awful really; way back in the 1960s we were talking about community care and better day

services and we haven't really progressed very much, have we? I'm in the process of collating a letter to go to the Director of Social Services pointing out how many 70- or 80-year-olds we know of in the community who are looking after a 50-year-old child, and there will have to be provision very soon for these older men and women. As ever, the people who are most deprived are the people who stayed at home because they never make any demands. The young ones now are making the demands and are taking all the time of social workers. Yes, while you carry on, you can. Oh yes, it's always been that way. There were people for whom it was such a blow; they just curled up inside and closed the door to the world.

I don't think I'll ever give up till I die. No.