



Community Social Care *Bedfordshire MENCAP*

V/o:

A history of Bedfordshire MENCAP. The National Association of Parents of Backward Children was formed in 1946, an organisation we now know as Mencap. You will hear from parents who contributed to the development of the Bedfordshire branch of the organisation. First, one of the founder members talks about her experiences of caring for her son with a learning disability before the advent of the society, and how the society was set up.

Brenda Nickson:

Well my name's Brenda Nickson and I had my son in 1955 and I was just told that he was a mongol, as they were called in those days, and there would be no future for him, he'd probably die when he was five, he wouldn't probably, well until that age, he'd probably not live longer than five and the best thing for us to do was to put him in an institution which of course, needless to say, my husband and I were just so horrified we just picked up our bags and left. I had a good, well I had a good weep, of course I think I spent the first two years crying, and we were just left then and at that time of course nobody acknowledged you to any great extent. My mother-in-law wouldn't acknowledge that there was anything different from Roger that except he had a bad heart, and I was referred to Hammersmith, and he went in for the investigation to see, x-ray the heart, see what holes were in it. When we went to collect him the specialist said that he was very sorry but he couldn't do anything for Roger and in any case he would still be a mongol, and it was the last remark that really shook us because we knew perfectly well he was going to be a mongol, that could never be repaired. In those days the baby clinic was once a month in the village and the health visitor notified my husband and I that there was going to be a meeting in the town of people interested in setting up a branch of the society for the parents of backward and handicapped children, and would we like to go. And I think my son was four months old then so it was very early on in the circumstances and we said yes. I can't remember how many people there were there, I was the only one with a baby, all the others had practically, you know, growing up children, and then so they decided then to form this branch of the society. There was no such thing as respite care or carers or anything at all, there was just nothing, and so the aim was to see about that, helping each other we were, it was like a self-help society, of course, and to try and get all of them recognised as people, you see respite care was the culmination of a long effort because the first sort of respite was having a night out at a club, and that was one evening that the parents had without their offspring. And that was the first sort of respite for the parents to get initiated into letting their children go somewhere where they weren't in charge of them. And that was another thing you see, and the society, the members of the society were adamant that there's no reason for their offspring not to have a club to go and meet like other children, other people did, and have activities that they could do.

V/o:

Brenda's husband, Jim, became chairman of the society and along with other members he worked hard to improve the facilities and services available to their children. As Faye Bunyon explains respite for parents and breaks for families were their priorities.

Faye Bunyon:

Whenever parents got together one need appeared to be, and it came up time and time again, was holiday accommodation where we could take the children and they could have a holiday in private without being stared at, where they could take the other children as well. Many of their children never had a holiday, especially the more handicapped ones and we fancied a caravan or a holiday chalet, and eventually Mr Nixon tramped round East Anglia looking for sites, and he came up with a site of a chalet in Winterton, and having got it he said to me you've made more noise than anybody else about this, there it is, you look after it. So I had a job of furnishing it with the help of quite a lot of local businesses that were very, very

generous. Social Services, yes were a little bit it's not going to work and I hope you know what you're doing, but we ignored those completely. Some parents said they wouldn't use the chalet, and they gradually came round to it.

V/o:

Brenda is certain that when it came to establishing provision for parents and children the voluntary sector laid the groundwork for the statutory services.

Brenda:

A lot of the services that are there now really have developed from the fact that they started as voluntary services, I mean who would have thought of them putting a swimming pool in St John's, I mean we used to take the boys you see as holidays and they went swimming and naturally Jim thought why can't we take, go swimming with them? And he got permission to have a swimming session at the college on a Saturday morning 12.00 till 1.00 when nobody else wanted it, and provided, we had to supply our own supervision of course and everything, but when it was first mentioned I can remember they said good heavens, you're not thinking of taking these sort of children swimming, that was the attitude. Who on earth do you think will go to look after them? It went like a bomb.

V/o:

After they became aware that their son Sandy had a learning disability Anne and Michael Tombs also became involved in Bedfordshire Mencap. They believe the society did provoke changes in care provision for those with learning difficulties.

Anne:

Well I think Mencap's been very important right from the very beginning, I feel that it was pressure from parents, and from parents' organisations that led to the complete change we've had in the last fifty, more than fifty years in the time when people just went into an institution to the position we're in now where people have rights and have choice of occupation, and a choice of residential provision.

Michael Tombs:

As it developed it did get a lot of people involved whose relatives were in the institutions. I refuse to call them hospitals 'cos they're not really hospitals at all, they were just institutions. And they took a different view and they felt that, you know, the provision should be centred round and they could improve them, they thought, a lot but they didn't really envisage the complete shift in the basis of provision that did develop eventually. We strongly promoted residential care and that was enough to alienate a lot of the people with relatives in the hospital 'cos they didn't want that.

Anne:

I mean I think the Education Act in particular was the most important, and the Chronically Sick & Disabled Persons Act as well, the change from health to social services was all part of that recognition that there should be services in the community, and I think that was largely because parents were saying we want something better for our children who are in the community, and we don't want them to go into institutions and we don't think that's the right place for them.

V/o:

With the closure of the long-stay institutions people with learning difficulties necessarily achieved a greater visibility in society, but voluntary societies like Mencap still found prejudice in health and social care.

Michael:

One of our members needed a cataract operation and the local hospital refused to do it, we were told, and so we quite simply said right, we'll raise the money to have it done privately, we will give this maximum publicity, and we'll march up and down outside the hospital waving banners. And the hospital, presumably the consultant in question, just changed their mind, and I believe the operation was carried out fairly quickly. And that was just the watershed.

Before they wouldn't, or at least they were extremely careful about omitting people with learning disabilities.

V/o:

In order to create greater awareness of people with learning difficulties it was important for Mencap to disseminate information and create a supportive network of parents. One of its most successful ventures has been the Welfare Visitors Scheme, thanks in part to committed volunteers like Beryl McLennan.

Beryl McLennan:

I think Mr Nickson probably thought there was a need for welfare visitors because a lot of people didn't come forward to join Mencap, they weren't involved, so there were lots of people out there with children and adults with a handicap that weren't getting the help and support. I mean it was obvious social services couldn't personally visit every family with a problem so he came up with this idea, and he got together with social services so it wasn't just, you know, him on his own, he did it properly. We had a member of social services all the way in the planning stage and everything. I think it's made a lot of difference, especially as befriending because a lot of people, I think sometimes you think you're the only one, you're the only one with a handicapped child or adult, you're the only one, you know, coping, and then you find out there's more, and another way it's helped is with benefits 'cos a lot of people were not getting their right benefits, they didn't know what benefits they should have and nobody told them.

V/o:

Beryl recently won an award for long service to the society. She's seen the community she serves change, presenting fresh challenges.

Beryl:

At one time I don't think I had any Asian families on my list at all. Now I think about ten percent of my list is Asian families. I mean it did start at St John's School, they got a group together to get Asian parents together because they really felt they were isolated, especially in their community when they did have a handicapped child, and they asked me to go along as a welfare visitor to advise on grants and benefits, that type of thing, and that's how I initially go to know families, Asian families, and that's many, many years ago and I'm still visiting them. Things have changed because we've not got Asian families very much involved. I find that the children, school age children, tend to translate if the mums haven't got much, you know, English language, but it's all worked out quite well really.

V/o:

The move towards complete integration into the education system and the community has been welcomed by many parents, though some regard these developments with caution.

Anne:

It's going too far with the idea of progressing towards normality because after all people have got a learning disability or a mental handicap, and so they do need a lot of support and help. And I do think that it's up to the younger parents now who've perhaps come up with greater expectations to see if those things can work in the future.

V/o:

Younger committee member Kim Bell says there's been a definite shift in expectations.

Kim:

I do feel that sometimes at committee level often its views of older people with learning disabilities are being aired, there's not a lot of new people coming in with younger children. For instance, going back to education a lot of new parents wish their people, their children to be, to go to school within the local community, whereas the people with older children fought for special schools, and that's what they wanted, but the current law does say that children should be going to their local schools. Our aim is for Simon to be able to be as independent as possible living in his own flat, with or without a friend, to be able to go off to work two or three days, to go off to college two or three days, Barnfield College gives good service every

Friday he goes now with his friend, so he has his leisure, his social activities, as well as an independent, but useful life. He does have a lot to offer.

V/o:

And terminology also provokes debate between the generations.

Anne:

I think it was last year they had their 50th anniversary and I had hoped as a parent that they would take that year to change their name because Mencap, we all know what Mencap, you know, stems from and I just think it's a wrong impression, mentally handicapped is not what we want to hear. And if you listen client groups, people with learning disabilities who meet together, they don't want that term either.

V/o:

Mencap's aspirations have developed and moved on. Founder member Brenda Nixon hopes this process will continue.

Brenda:

It's only the people involved in the problems that can see ways ahead, and as new ideas come I hope that they will be accepted. You see the whole attitude of the world of the approach is so, has jumped so much, you know, that I just hope that it goes on.