## THE HISTORY OF KINGSTON MENCAP TO 1982

Late in 1946 a young mother of a mentally handicapped child wrote a letter to the 'Nursery World'. This was replied to by another mother who was the person who initially started our whole National Society and still takes a leading part. Other parents got in touch and they sent a letter round, each adding on a bit. The picture was tragic. She resolved to form an Association of Parents of Backward Children. The 1944 Education Act had deemed those with an I.Q of under 50 as uneducable. A dreadful term for parents to hear, the uneducable attended occupation centre where these were, while others stayed at home. The first issue of The Parents Voice was in 1950, the same mother who had started it all was its Editor and she continued in that role for the next 25 years.

The first three local societies were formed in 1947 and 1948 and many articles found their way into newspapers and journals, highlighting the needs of the mentally handicapped and their families. In the spring of 1949 a conference was held at the Fountain Hospital, then a collection of huts. In 1950 the first Annual Convention was held also at the Fountain Hospital and the decision to change the name to the National Society for Mentally Handicapped Children. In 1979 the words 'and Adults' was added, and in 1981 the Society received the Royal Charter, becoming the Royal Society for Mentally Handicapped Children and Adults, for general purposes the name to be shortened to Royal Mencap. The Queen Mother had been Patron since 1962.

By the convention of 1954 there were 167 local Societies, ours being one of them. Wimbledon had formed a Society which covered a huge area and some parents from Kingston went to the meetings. In 1952 a Mr Spooner came from that Society to a meeting held in Kingston and from that started the Kingston and District Society for Mentally Handicapped Children. The Chairman for the first year was Mr Tom Balding, its Secretary for 11 years was Mrs Monk and a friend of hers was Treasurer for one year. An appeal was put in the local press for cash and to find other parents in the area, with letters being sent to local firms. They received £25 from this to start off the Society, the hire of the hall for the meeting being £1. The subscription was 3/6 of which 2/- went to the National Society and included the Parents Voice magazine which then cost 6d. It was said when the subscription was fixed that it should not be more than the cost of a packet of cigarettes. That still applies to our subscription many years on, but thankfully many members make it a great deal more.

#### How the societies grew and divided

In 1958 there was a joint meeting of the Sutton and Kingston Societies to discuss the boundary between the areas with particular reference to Epsom and Ewell where there was an overlap. It was unanimously agreed the time had come for some reform. Kingston's area was much too large to be workable, stretching as it did from Barnes to Leatherhead. Both Kingston and Ewell had an Occupation Centre and it was obvious this was a natural focal point and an attempt should be made to start a new Society to serve the needs of Epsom and Ewell. The

inaugural meeting was on the 7<sup>th</sup> May 1958 and a £10 donation was given to start them off. It was still felt that our territory was too large and after discussions an inaugural meeting was held at Mortlake on 21st November at which the Richmond and Barnes Society was formed, again with a £10 donation to see them off.

Many of the people still came to the Kingston Occupation Centre and much later to Dysart School and onward to our Adult Training Centre. Their own Training Centre came some years later. Many came to our Youth Club retaining old friendships One thing our Society is fairly unique in, is that in 30 years we have only had three Secretaries, one for 11 years, one for 14 years and the present one for five, and still going strong. Our equipment is of the same durability, originally a second-hand typewriter was purchased and used by various people in the Society for many years, a second one was got some ten years ago with Green Shield stamps and a third has recently been purchased, again second hand. Other people use their own. Our first duplicator came to us on permanent loan from a large firm in 1960. When we purchased a new one in 1970 the firm insisted on giving us something for the one we had had on loan. A third one is now just being purchased.

The aims of the Society in its early days were to:

- Promote the spiritual, mental and material welfare of mentally handicapped children.
- To encourage research into the causes and treatment of mental handicap.
- To foster mutual help and support among parents and relatives of such children.

Later they widened to become and still are:

- To give practical help wherever possible to the families of the mentally handicapped.
- To ensure that the retarded person has the chance to live his/her life to the full.
- To provide social activities for the mentally handicapped and parents.
- To work for the best possible relations between the statutory services and our voluntary organization.
- To educate the public to the needs of the mentally handicapped and to gain their sympathy and support at local levels
- To fundraise to provide the extra equipment for the various establishments connected with mental handicap in the Borough and subnormality hospitals connected with it and to provide social activities and run our mini-bus.

At the end of 30 years I feel we can look at these aims and say we have gone a long way to live up to them

# Giving our young people what they needed

Our main purpose was to pressure local authority to make proper provision for our young people. They were in an old church hall with no outdoor play space and they were not allowed to play cricket on the local recreation park because they were mentally handicapped. No equipment could be left out overnight and everything had to go into

one cupboard, so it was very limited. A few years later the church allowed us to install a cooker so that the girls could learn to bake – but on condition it was the church's property.

There was one toilet which kept overflowing and it was the Secretary's long task complaining about the toilet or that the heating had broken down. There was also nowhere to wash - the boys handed bowls of water through the kitchen hatch to the girls to place on a long form and wash there, whilst the boys washed in the kitchen. There was no telephone, but two very kind ladies in the local terrace of houses allowed us to use theirs in an emergency and followed with interest the progress of the youngsters, so much so, nearly 25 years later we received a handsome legacy from the surviving sister.

We at that time came under the Surrey Authority, a Surrey group of Societies was formed to help bring pressure on local authorities, in particular the health field to bring the needs of the various areas to their notice. The Secretaries all exchanged newsletters and though we are no longer in Surrey those societies who later came under the G.L.C. still to this day exchange newsletters. By 1958 it was obvious that endeavours to arrange outings on a Saturday for the Society met with little response. It was decided to approach the local authority and see if we could run an outing for the occupation centre. This offer was accepted with much trepidation as to the rightness of it all, it was very successful. We had a coach to Ranmore Common for games, then to Chessington Zoo.

Two more successful outings in following years and then the two ladies who arranged them got ambitious and went by coach to Runnymede for games and picnic, then to Windsor from where we had hired a steamer to go upriver to Marlow with tea on board. I can well remember just how mad the two organisers were thought to be. It was anticipated that youngsters would throw themselves overboard at regular intervals, in fact they all behaved beautifully. Fewer mothers worked in those days, there being less part-time employment and they all joined in the outings and we all knew each other and our problems in a way, which is not possible now.

These outings helped to show the public, a little to their astonishment that the mentally handicapped were real people and could behave themselves and go places, so as well as enjoyment for the young people they were the forerunners in educating the public. These outings continued for a few years after the new school opened and then they made their own plans for more seaside type of visit.

One of the two lady organisers was Mrs Winter who became our Treasurer in the second year of our Society until her death in 1963 and her drive and forethought for the needs of the handicapped was a lasting inspiration to many. Her husband continued as our Treasurer for many years, having been National Association of Parents of Backward Children's first Treasurer, he was our nominee member for many years and latterly our much respected first President.

### Achieving public recognition

A large part of our work was to bring the mentally handicapped into the public limelight and teach the public to accept them, which they very much do now but always there are a few exceptions and consequent hurt for parents. From the first learning their child is mentally handicapped, their vulnerability never really leaves them. In this field the work of the School and Training Centre with their social training programmes and getting out to places has helped greatly.

Welfare and help to parents has always played a large part in our work, parents can feel very alone, especially when a new baby is born. It was our concern in the early days that we seldom heard of a new baby and as the occupation centre did not take in children until they could feed themselves and were toilet trained, the mother was isolated at home and received no expert help as they do now. The very earliest a child could get into the occupation centre was five and some were eight before they could be accepted. It was only then, that we often learned of these children.

The hospital was not at all helpful and it was only the coming of a new paediatrician some eight years or so ago, which made such a vast difference to our work and now we get to know parents of very young children, if they so desire. Our main pressure area had to be getting our children out of this old church hall and if possible into purpose-built premises. From the time Surrey gave their agreement to this, it took eight years to come to fruition. Three sites were lost because neighbours or owners of land did not want mentally handicapped near them. At last ground was found on part of the land of the Cassell Hospital, but coupled with the insistence it had a high brick wall round the new building. We parents resisted this but had to agree or see the site lost, so our 'Terrible' children were fenced in. It did not keep them in, 18 years later the children's own charm has got over the wall and there is now a Friends of Dysart group, made up of local residents taking a very real interest in the school.

It is almost beyond belief, but it took the firm – never more than two men on site - three and a half years to build this school. Every six months we were promised we would be installed by the next term. Letters and threats of a march of parents down Clarence Street went to Surrey County Council. The letters kept flowing but too little avail. One feature in the delay in finding a site was that we learned there was only one special care unit in the country and it was at Hanworth.

Three members visited it, one being Mrs Winter and perhaps our special care unit is her best memorial. They drew up a paper and it was rushed down to catch a Mental Health Council meeting with an offer to raise £1000 to build this unit on to the school. They were so impressed they agreed to incorporate it into the plans and that every future Junior Training Centre built in Surrey would have one and they would nor accept our £1000. This unit was to cater for the very handicapped, often multi-handicapped children who just had to stay at home. Now these children are in their twenties and no longer eligible for school, so we find ourselves in the throes of pressing for further facilities for them, as we have been doing for some years past.

#### The early days of Dysart School

Dysart school was eventually opened in the same year as the Greater London re-organisation came into being – 1965 - and for some terrible months it looked as though our school (or as it was then the Junior Training Centre) for which we had fought for so long, might come into the Borough of Richmond, but to our great relief when G.L.C. boundaries were finalized, it fell on the Kingston side, but only by a few hundred yards. We left the old occupation centre at Christmas full of the pleasure of a bright new future at Dysart in January. Then in one tragic swoop, those children who now lived in Surrey and went to the old occupation centre and had been our members, were overnight denied the use of Dysart School. This was a terrible and cruel blow dealt in the Christmas holiday period. We lost many friends who had worked with us for so long, and our joy in our new Centre was dimmed by the thought of those deprived the use of it.

For so many years while waiting for the new premises, the parents of older children had dreamed of a workshop where they could do contract work and be real people and have a pay packet in their hands. This wish was granted when an extra outer building was erected at Dysart for this purpose. All too soon parents realised how short sighted they had been – or did our young people develop so well in their new setting that we had to make our thinking catch up? Life was not made up of sitting at a bench and doing unimaginative work and nothing else. Certainly the pay packet once a month was a great excitement with the young people, but it became obvious they needed a much wider field.

At 16, the young people had moved from the Junior Training Centre to the workshop and it was impressed on them how to grow up. They were now and would get paid once a month. In being grown up they had to adapt to the terms of industry and did not get paid for the first month. They had to work for two months before being paid. Many a mum collected a sad child from the coach on the first pay day, I still remember my own daughter's searing sobs when she saw me, the mutters that she had not got paid and everyone else had. I do not think the pay when it came ever meant the same, fortunately they are now paid weekly.

Some six years later, and with no pressure from our Society an Adult Training Centre came into being, but it was to incorporate a laundry. At our A.G.M. we had invited the Deputy Medical Officer to speak to us about this, and voiced our fears but were assured it was all perfectly in order for our young people to work in such conditions. We were not wholly re-assured and fortunately for us an imaginative manager was appointed to oversee the building and development of the new Centre, whilst also being the Manager of the Dysart workshop. His views were the same as ours and within days of it being too late because of the placement of drains, the laundry idea was dropped. That was the moment we went from Edwardian to Modern Times.

In the place of the laundry, there is a whole live unit – comprising a large workshop for contract work, a metal workshop and a woodwork- with machinery and tools which petrified parents on first sight, that they almost wished the laundry back. Now it is quite taken for granted that the young people can work competently there with

skilled staff. When the new centre for the handicapped was added on as an entirely separate unit, the woodwork shop turned out most of the fittings for it. As well as these things there is an art room and pottery, a domestic unit and a hairdressing salon used for social training purposes, a gift from Society. Since then there has been added a photography room, again a gift from us, which recently brought rich rewards in the form of some of our young people winning an international award for photography. Other helpful gifts have been very high-grade physical education equipment and a complete radio service, so that the trainees can have discos for special occasions, but more important they have regular broadcasts done by the trainees themselves complete with record requests. Apart from enjoyment, it is helpful for language development and speech plus other subtle ways of development.

This was a follow on to our principle when Dysart School was opened. We initially put £1000 worth of equipment into it and many more items since and this will be our continuing policy. Our relations with both establishments are very sound. Like most schools Dysart formed, in time, its own P.T.A. but again relations between that and the Society have been friendly. The Adult Training Centre looks upon us as their friends group. It is very hard to refer to Dysart as anything other than a school now. When it opened it was a Junior Training Centre but about five years ago, such establishments became schools under the new Education Act whereas before young people went at sixteen on to the workshop at Dysart, and later to the Adult Training Centre – some stayed longer if it was beneficial to them. Now under the new act, they could stay on until eighteen years and ten months. This has proved very beneficial in the new educational and training programmes, which have been built up. Another very beneficial progress is, that children are now accepted at two years of age, unlike the vastly opposed to five years of age at the old occupation centre, if they were lucky.

# Support living accommodation

Our other pressure for so many years has been for hostels and it has been a hard struggle, it was a long hard push to see the first one established and then a junior one was provided, but still more room was urgently needed above all for short term care. We were almost on the decision on a new purpose built one, when a financial crisis came along and the Council could not proceed with it. A few more years elapsed and a beautiful old house was made available and conversion was finished, staff about to be advertised for when along came the present financial crisis, So tragic, as so much good work had been done in liaison between Social Services and parents, with many meetings to work out where the real need was. It was a terrible blow, but it was either our hostel or the shutting of an old people's home – understandably we lost.

A semi voluntary way of opening it was found, with joint funding from the Social Services and the Society. The Social Services contributing the equivalent of the cost of mothballing the building and various other methods, and the Society making a contribution for the next three years. It has provided a good home for about 12 and quite a bit of short stay care, but alas it does not provide for the less able for whom it was originally intended and this causes great concern. Being run on a semi voluntary basis they can only cope with the more ably mentally handicapped person. Parents with a severely handicapped youngsters do a tremendous job in keeping them at home, and others like them need a break. Because there is no doubt that if parents can have a break from time to time, they are much more able to carry on. We now have a high percentage of parents in there sixties, seventies and eighties, and now one in the nineties still with their children at home with them. Apart from relief for the parents, it is essential for the mentally handicapped to get used to hostel care for short spells. This prepares them for the time when they must have a new home. Ideal conditions would be that this could begin in their teens and like their other brothers and sisters leave home in their twenties but this is a long way off, and there are so many older parents needing help.

Welfare is being increasingly needed now, possibly because, school and training centre are now planning many more holidays and activities from camping, chalet hire, Crystal Palace visits regularly, to day trips abroad and some ski trips from Dysart.

Such holidays are more costly for parents now and we help in an overall way with these holidays, also community nursing holiday as well as our private and confidential welfare work.

## **Essential fundraising**

We must raise money to keep things going, the purchase of a new mini-bus now would make a large hole in what we know is a good bank balance, which would have stunned us some years ago. We do not appeal to the public for money, but many organisations have been very kind to us and we had a legacy, which with good investing and higher interest rates has seen our funds boosted, it would still take only a few very major items to deplete it. Christmas card sales are our main source of revenue. We also run Jumble Sales, Derby Draw, Christmas Bazaar and odd stalls. Records of our Christmas card sales make for interesting reading. The first record I have of sales is in 1956, with a turnover of £150 – profit of about £30, doubling the next year to a profit of £63. By 1962 we first broke the £1000 mark, with sales of £1060 – a profit of £275. By 1971 our profit was £840 and by 1981, it was £2893, and by 1980 we had broken the £10,000 worth of sales.

Our minibus is an essential part of our work, our first one in 1965 was bought with money raised by Kingston Students' Rag Week. It was bought second-hand from the Red Cross for £400, this was used until 1969 when it was handed over to Dysart School for their use. In later years the Society replaced it with another better second hand minibus for their use.

Our present minibus was given to us by the Molesey Festival Society who raised £625 towards it, the Society added the necessary £395. Its main purpose over the years was to take parents on a Sunday visit to their offspring in residential care at Botley Park Hospital, Chertsey, which until eighteen months ago was our local subnormality hospital. It is unlikely those resident in Botleys will ever be moved now and parents are not so young now, so our Sunday service to them is essential, as transport to Chertsey is nigh on impossible.

Its other important duty is doing transport for our Youth Club. It does two runs each Wednesday evening, one round Malden and one round Surbiton/Chessington, bringing young people to club who do not have other sources of transport. On the return journey it does only one trip, as kind parents and friends come and help with transport so that young people are not too late home.

This Youth Club is nearing its 21<sup>st</sup> Birthday. Originally it was called the North Surrey Youth Club for the Handicapped, being a joint effort between ourselves and the Spastic Association. The latter withdrew after a time and we carried on. Again it was an old Church Hall, nor ideal but it has always been a happy club and popular, as evinced by the lads and lassies who still come each week from Richmond. At one point we could have used good school premises but after consideration, decided to stay in the hall, which we still use.

From small beginnings 30 years ago we now have a Society of 165 families who have known mental handicap and 38 members who are sympathisers. Tending to get a little large perhaps in that we do not all know one another as we used to, a newsletter was started in the Society in 1961 to go out monthly and has done so ever since, this is an important part of our communication with members. At other times, it is wonderful what the old bush fires can do and we only find out when the questions come in.

It is our job to keep us up to date with all the new information about allowances, legal matters and many other problems. For much of this information we rely on our Royal Society. Nowadays, it is almost a full-time job keeping up to date and though in the early days many members worked hard raising money from scratch and pressing for decent and better conditions for our young people – many of those young people now in their forties and maybe fifties – at least there was one goal members were working for any new developments in allowances etc., were few and far between.

Now we live in a sea of paper, all of us voluntary people, mostly parents coping and, of course, the more we liaise with the statutory bodies the more we must keep ourselves up to date. Sometimes I fear older members can get a little irritated at just how much the good conditions are taken for granted – going to Dysart at two Social Services help, community care, good equipment, youngsters doing things and going places from Dysart, A.T.C. and Hostels, we never even dreamt they were capable of doing. Those older members should not be irritated, as these things are just exactly what was fought for so hard in the early days and it is rewarding to see it all happening. Sadly, there will always be a gap in the ability of those who did not have the opportunities when they attended the old Occupation Centre and those of later years who did. For all it is so much wider a way of life and will get much wider yet, it will be the Society's work in the future to see it all happen. In one short 30 years it seems like a revolution in thinking and caring.

# Written by Chris. B. Conacher 1982.

THE ABOVE WAS APPROVED BY THE THEN SECRETARY MRS EDITH MONK AND MR SAM WINTER THE THEN CHAIRMAN OF OUR SOCIETY.