

# TWO DIAGNOSTIC CLINICS FOR RETARDED CHILDREN

By Shelagh Tyrrell

"A HANDICAPPED child is a child who cannot play, work or do the things other children of his age can do, or who is hindered in achieving his full physical, mental and social potentiality . . ." This is the definition of the 1960 White House Conference on Children and Youth. President Kennedy, in his short, meteoric term of office, gave a tremendous boost to the parents of these children, and to the medical and social agencies concerned with their welfare. His special concern for retarded children can probably be explained by the fact that one of his sisters was mentally handicapped.

## Immense problem

The problem of the handicapped child there, as in every other country, is an immense one. It is estimated that one out of ten children born in the U.S.A. has a handicap sufficient to interfere with his full development. An inspired effort is being made in several places to touch small areas of this problem, and I was privileged to visit one of these last summer. It is the Hamilton County Diagnostic Clinic for the Mentally Retarded, and it is situated in a residential suburb of Cincinnati, one of the more interesting towns in the State of Ohio.

The clinic grew from the efforts of a number of parents of mentally handicapped children. In 1947, a group of these parents started a system of training classes. By 1956, they had sufficient support from interested professional people to persuade the County Department of Health, the County Department of Mental Health, and the Children's Hospital of Cincinnati, to sponsor a clinic with a seven-point programme, comprising—diagnosis, prognosis, information, exchange of information, research, training and, lastly, education of the community in respect of mental health problems. One of the reasons for the success of the clinic has been the support they have received from private doctors, who normally regard any

agency that smacks of State control as an incursion into their jealously guarded territory. This support is understandable when you consider the frustration which doctors often feel when faced with a problem they cannot solve. Where his professional skill seems to be of no use to him, where his training is often grossly inadequate, and where his own, possibly unconscious, beliefs may interfere with his judgment, he can often be of little real help.

Since mental retardation can arise from so many causes, parents may have to go from one expert to another, each willing to help and advise in their particular field, but none perhaps prepared to fit the pieces of jigsaw together into a whole. The clinic has been founded to help these parents, who otherwise may feel compelled to wander the country, pursuing the most unlikely glimmers of hope, often at considerable expense to themselves financially, and to their families in terms of happiness and stability.

## Long waiting-list

The waiting list is a long one, in some cases up to 18 months or two years. When the parents are first referred, they are asked to fill in a questionnaire which concerns the child's present state, as well as a very detailed developmental history. This not only helps diagnosis, but makes it possible for the staff, ever-conscious of the long waiting list, to accept only those cases they feel can be really helped. If the child is accepted, the parents are interviewed by the psychiatric social worker when his turn comes. She collects more information and, in particular, tries to find out what exactly the parents expect and hope from the clinic.

With the original questionnaire, "test papers" for detecting phenylketonuria are sent to the parents. This is not, as one might suppose, to make sure that treatment is started if the test is positive. By the time a child is retarded enough to warrant investigation, he is beyond

simple treatment measures. It is to make sure that if the mother has recently had another child, or is expecting one in the meantime, treatment can be started for the new baby, if it is found to be necessary.

### Detailed examination

After the first interview, there comes a detailed medical and dental examination, and an expert speech and hearing test. If it is considered necessary, the technical assistance of the next door Children's Hospital is obtained for any biochemical and pathological tests, and consultants in the various departments may be asked to advise on individual problems. The psychologist now takes over, and tests the child's intellectual functioning. The Public Health nurse, in this respect like our Health Visitor, calls at the home, to see the child in his own surroundings. The evidence is then collected together by the doctor in charge of the case, who will present it later to a group of interested colleagues, including the patient's general practitioner, as well as representatives of appropriate agencies (of which there are very many). They discuss the diagnosis, the age at which the child is functioning at present and his capacity for future development, and whether there are any recommendations for present action. The parents are seen again, once to explain the findings, and again a week or so later, to discuss any points which may have occurred to them after a few days of meditation.

An attempt is made to obtain follow-ups. Ideally, the clinic staff would like to provide continuing guidance for the parents, whether directly or through general practitioners, but there are not yet the facilities available for this. As it is, they give the parents support, which many of them so badly need, and give the family doctor the confidence of a specialist diagnosis and evaluation. They educate medical students, paediatricians, psychiatrists in training, social workers and public health nurses. All these come to the clinic, talk to members of the staff, and attend their case conferences.

Whilst aware of all they can do, the

staff admit what they feel they have not been able to achieve. The problem is enormous, and very few children in need of this thorough assessment do, in fact, receive it. Many who need it most are most difficult to help, in particular the psychotic child, the child with multiple handicaps, and the child who cannot talk. How do the clinic staff see the future? With well-trained and interested people, it should be theoretically possible to screen all the preventable causes of mental retardation, and give early detection and diagnosis of the rest. There could be support of the family, and parent-counselling. All the problems which might have to be faced, such as institutional care and "what will happen when I die, or grow too frail to care for him?", can then be discussed in a sympathetic and familiar atmosphere, and in the full knowledge of community support and care.

But much of this is in the future, although a most encouraging start has already been made due to the enthusiasm and concern of individuals, and in spite of an enormous amount of red tape. Money in the United States is always readily forthcoming for research purposes. This is high-minded and harmless, because it can offend no man. Yet even internationally-renowned institutions can be hampered continually by uncertainties about financial support. If there is sufficient publicity involved, they will be saved from the axe, but rarely earlier than the eleventh hour, and then with a promise of funds often for the immediate future only. The clinic at Cincinnati is much more secure than most, because of its sponsors. But there are still not enough clinics like this to do more than touch the fringes of the problem.

I visited a similar clinic, run on rather different lines, in London. It was founded originally as a haven for those parents who were told that their children were ineducable. This, they knew in their hearts and in their homes, was not true. The argument was in fact only one of words. These children often are ineducable by orthodox methods of education, but this does not mean that

they cannot be taught if some system suitable to their particular needs can be found. And herein lies the success of the Rudolf Steiner schools.

The procedure in London is similar to that in Cincinnati. There is the same long waiting list, and although a visit from a social worker to the home is considered desirable, this is often impossible, since children come from such a wide area—in fact, from all over the world.

### Full history

The psychiatric social worker takes a full history, and here she is as much concerned with how the mother (and father) feels towards the events and difficulties they are discussing, as she is in the difficulties themselves. A test with the educational psychologist may follow, and then a clinical examination and assessment. Here, too, the parents are asked to return a week later, when they will have had time to think about the discussion, and may want more help. The children are seen regularly at first, so that a fairly accurate prediction of future development can be made. After that, they know they can return at moments of crisis, and these will be the same on both sides of the Atlantic—school placement, adolescence, work, or some unforeseeable event like the death or departure of a parent.

The two clinics show an interesting similarity of purpose and, in some ways, very different methods of approach. The Hamilton clinic is obviously anxious to give the parents their money's worth, and make sure that no stone is left unturned. The insistence on every child coming for assessment having a full dental inspection possibly suggests the pre-war days in England, where the patient with any obscure disease was subjected to the removal of all spare parts which might, remotely, be the source of the mysterious illness. This element of showmanship is conspicuously lacking in London, where the physical causes for retardation will have either been excluded before the child comes, or would be suspected in the initial clinical examination and then followed up. The London approach obviously depends more upon an

extremely high level of clinical acumen and understanding, and this without doubt is its strength. The approach of the psychiatric social worker will probably be the same in both places—a readiness to discuss problems, and to guide the parents towards making their own decisions, rather than handing out advice.

As in the United States, a service like this can touch only a very few, and perhaps one of the most important functions of the clinic will be in the training of medical students and social workers. After all, the person who can help more than anyone else will be the child's own general practitioner, and every doctor is likely to have at least one subnormal child on his list. He can, if he is interested, even anticipate the moments of crisis. But medical training generally offers very little experience of child psychiatry or the subnormal child.

### Counselling service

One need, which does not seem to be regularly provided by either of these clinics, is a counselling service, available to parents, and dealing with day-to-day problems as they arise. An interested general practitioner could provide this, if only he had the time. So could a child welfare clinic, if specially set up for this purpose or where the staff arrange a time which is kept especially for these parents and their children. University College Hospital has had an advisory service for the parents of these children for several years now.

So often, a mother will bring her mongol baby to the clinic until he is old enough to be "different"; until some other mother unwittingly comments on these differences, or until her child, who so needs to mix with other children, does something which arouses adverse comment. So much public money and energy are spent in advising mothers of normal children, and yet the very ones who need counselling, and who have many problems which might be helped by careful discussion, do not come. There are the problems of the five-year-old with the strength of that age and the behaviour of three; where to get outside nappies and plastic pants, or what is best

for skin constantly sore from dribbling. There is the feeling of hopelessness because constant repetition in learning has somehow not yet produced any results. There is the need for encouragement that it will do so in the end.

There are, of course, clinics for retarded children in many places, but with the numbers to be seen these are mainly for assessment, with infrequent follow-ups, and not weekly or fortnightly

counselling sessions where mothers can meet and chat over cups of tea. More often, they find this help at the meetings of their branch of the National Society for Parents of Mentally Handicapped Children, where there may be too little professional help available. Perhaps a combination of the two—a voluntary organisation with borrowed professional help from the Local Authority—might be one answer.

## RESEARCH INTO RESEARCH

by L. T. Hilliard

WHAT research into mental retardation is being undertaken in Britain at the present time? Who is doing this research and where is it being done? It is difficult to give accurate answers to these questions. Those who undertake research into one of the many aspects of mental subnormality may sometimes be unaware of what is being done in allied subjects, or even of the work of other researchers in their own field, if that work is not yet published.

### Collecting information

The British Committee for the Scientific Study of Mental Deficiency decided that one of its functions should be to collect information on mental deficiency research in Britain. If the various projects being undertaken could be collated and classified, it would be possible to issue a summary of them from time to time.

This Committee was formed in 1961. It developed from the steering committee responsible for the London Conference on the Scientific Study of Mental Deficiency, held in July 1960, which was sponsored by four professional societies, in co-operation with N.A.M.H.

The British Committee is a member of the International Committee on the Scientific Study of Mental Deficiency, which held its first congress in Copenhagen in August of this year. It is hoped that other members of the International Committee will compile similar information relating to their own countries, and make this generally available.

Owing to the inevitable delays in the

publication of papers in many scientific journals, research reports may appear some considerable time after the work has been completed. If information on *current* research work could be made more easily available, some of the projects might be integrated or correlated to give better statistical results. Not only might present research funds be used more effectively, but also, when the overall programme in this country was made plain, with its gaps and limitations, more money might be made available for worthwhile projects.

To collect information on research, letters were sent to local authorities, regional hospital boards and universities. An encouraging response was obtained and the Committee is grateful to all those who have troubled to reply to these requests for information.

### Reports received

Some twenty local authorities reported research projects, and sixty five sent a nil return. Several stressed the difficulty of initiating research when staff and funds were limited. Each of the fifteen regional hospital boards in England and Wales reported some research, though some regions such as the S.W. Metropolitan had many more projects to report than others. A hospital that undertakes research, even with limited funds, is likely to attract other research workers, and later to obtain increased facilities. (The Hospital Friends who threw their coins in the Fountain and wished, certainly started something.)

Hospitals for the mentally subnormal were then individually circularised, and