

# Trends in the Education of Children with Epilepsy

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I do not propose to treat this subject in any textbook sort of manner. There are various textbooks in which a more systematic treatment of the subject may be found, and I might also refer to my own booklet *The Child with Epilepsy in Your Class*. I would like to refer very briefly to some trends in the education of children with epilepsy to provide some background to the discussion of several surveys of South African epileptic populations which seem to me to have certain practical implications in the approach to the educational problems of children with epilepsy in South Africa. The findings of these surveys may also hold some practical implications for future action by the South African National Epilepsy League.

We all know of the existence of special schools for epileptic children in various countries, including South Africa. I do not wish to go into historical details or to enumerate these countries and their schools. Probably most of us also know that the tendency today is towards the integration of handicapped children into normal schools and away from special schools. There is, instead, a tendency to increase the specialised services available at normal schools to cope with the problems of handicapped children attending these schools. In the UK we have seen how this policy leads to a steady fall in the enrolment of pupils at special schools and the closing down of some.

We have, however, also seen the wheel turn completely in some cases, as for example in the USA. In 1935 the White Special School was established in Detroit. Its peak enrolment reached 200 but then gradually declined until the school was shut down in 1957 as a result of decreased need for its services. Now the Epilepsy Foundation of America has had to establish a rehabilitation Centre for children with epilepsy near Washington, DC, at great cost. This rehabilitation centre is just another special school, resembling most other special schools for epileptic children elsewhere in the world.

We also realise today that epilepsy itself is not a very reliable common denominator for the classification of children with the view to providing them with appropriate educational care and treatment. There are many other factors, besides their epilepsy, which have to be considered, e.g. intellectual endowment, emotional disturbance, behavioural problems, additional handicaps, etc. One aspect of which we are becoming particularly aware nowadays, concerns the problems of learning ability resulting from

the variable neurological handicaps to which these children may be subject. They may experience some of the specific learning disabilities which have become associated with conditions called by various names like brain dysfunction, psychoneurological disorders, neurodevelopmental learning disorders, etc. These conditions may actually be more relevant to their educational difficulties than their epilepsy *per se*. Such a learning disorder requires specialised educational methods and facilities. These are increasingly being provided in the school systems for many other children who suffer from the same or similar learning disorders. This tends to become a new common frame of reference for the provision of educational facilities, methods and treatment for similarly handicapped pupils. I shall not pretend that much of this is to be seen in South Africa, but there are at least a fair number of educationalists in South Africa who are seriously involved in these aspects of education.

In this paper I propose to deal mainly with children with epilepsy who attend ordinary schools. Unfortunately we know very little about them except that they are definitely there and that they presumably cope reasonably well with the education provided in the ordinary primary or high schools, in special classes for the educationally or mentally handicapped children, and in some cases in vocational schools. But we know practically nothing about them and we are unable to judge the adequacy of the arrangements made for them.

I therefore wish to deal with 3 reports of persons with epilepsy, 2 of them concerning children only, which have been made since 1962 and 1963 in South Africa by the Human Sciences Research Council, formerly the National Bureau for Educational and Social Research. Unfortunately these reports refer only to Whites. Regarding the problems of children with epilepsy in the various other racial groups of the South African population we still know virtually nothing. The special school for Coloured children with epilepsy at Worcester has been in existence for some years. We therefore know at least something of the problems of children with epilepsy in the Cape Coloured group.

The first report to which I want to refer was published in Afrikaans under the title *Aspects of Epilepsy in the Republic of South Africa* (Research Series No. 56). It concerns 600 White epileptics selected by chance out of a total of 2 226 living in the community. As the survey gave an incidence of only 1.07 per 1 000, they can unfortunately not be considered representative of all epileptics living in the community at that time. The findings must therefore be considered as tentative only. Even in this group there was an indication of a higher

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incidence, although slight and inconclusive, of epilepsy among Afrikaans-speaking people than among those speaking English. The educational standard in this group was dismally poor. Only 12% of them had, at some time, attended a special school for epileptics. Some had been at school before special schools for epileptics existed. Only 1,1% had an education beyond the matriculation certificate and only 5,1% attained the matriculation certificate. About 53% completed their primary education. Some 30% could barely be considered literate.

Some findings which characterise this group are worth considering: 25% had no friends and 28% had 1-3 friends; 76% belonged to no society or association, or to any social organisation; 52% had no hobbies; 50% declared that they enjoyed being completely idle for long periods of time; more than 50% declared that they were not hampered in their movements at all by epilepsy; and of those old enough, 6% were in possession of a driving licence.

Most of these findings point to shortcomings in the experience and adjustment of epileptics which their education should endeavour to prevent.

The employment history of these epileptics also constituted a dreary tale. Of the total investigated, 280 could be considered possible candidates for employment on the open labour market. At the time of the investigation 77 who had previously worked, were unemployed; 88 had never worked; 22 were in sheltered employment; and 93 were employed in the open market.

The 93 in the open labour market were employed as follows: 28 did clerical work; 13 were skilled workers; 25 were semiskilled and unskilled; and 27 had a variety of other jobs (farmers, or in personal services, etc).

Of 65 cases who had become epileptic after starting work, 26 had remained in their jobs, whereas 28 were dismissed because of their epilepsy. Of the 93 currently in employment, 40 declared that special concessions were being made for them in their jobs because of their epilepsy. In 41 cases the employer was ignorant of the employee's epilepsy.

The financial conditions of the epileptics investigated in this survey were analysed in great detail. On the whole it was a tale of poverty and in very many cases one of real hardship and deprivation.

One very interesting finding concerns those epileptics who had married and had children of their own. One hundred and forty-three of the group in the survey were, or had been, married. Their offspring numbered 338. Of these, 8 had themselves shown symptoms of epilepsy.

The second report to which I wish to refer, concerns a very limited investigation. It was undertaken by the HSRC for a Government Committee of Inquiry into the provision of educational facilities for children suffering from chronic diseases. Epilepsy was included in the list of chronic diseases. Unfortunately the report of the Committee was not published, but SANEL obtained some statistics of an investigation of children with epilepsy at school and permission to use these figures.

The investigation seems to have been undertaken with the sole purpose of establishing the number of children

with epilepsy attending ordinary schools who might be considered to be candidates for a special school for epileptics. The criteria for this seem to have been uncontrolled seizures and mental retardation. The statistics are arranged accordingly.

By means of questionnaires, principals of schools were asked to give information about children with epilepsy, and 1054 such children were reported, 198 (19%) from special schools for epileptics and the rest from ordinary schools. The total school population concerned which this figure represents, is not known. It is believed to be an incomplete return, but to what extent is difficult to say, since it cannot be calculated from the total school population, because some questionnaires were not returned.

Four hundred and thirteen children were considered to have their seizures unsatisfactorily controlled. Of these 276 were considered to be mentally retarded and thus doubly handicapped, and could presumably not be catered for satisfactorily by the ordinary schools. Of these 276 pupils 118 were attending ordinary schools at the time of the investigation, 47 were attending schools for vocational training for the mentally handicapped, and 93 were already attending special schools for epileptics.

From these figures it did not seem that there was a large reserve of candidates for admission to special schools. It is interesting to note that of all pupils with epilepsy, 61% had their seizures satisfactorily controlled. In the case of those attending special schools, this figure was 41%, whereas it was 65% for those attending other schools.

The third report I wish to examine is a report on the epileptic child in Standard 6. This is report MT-7 of the HSRC. It was published in 1971 but concerns a survey of 1965 which included 69 908 White children then in Standard 6. The report arose quite incidentally out of the larger project concerned with the investigation of manpower available in the country. The children were selected on the strength of their own reply to one of the biographical questions included in the survey, which was 'Which of the following causes you most trouble?', one of the physical ailments listed being 'falling sickness'. This seems to be a rather slender basis for selection but it gave a surprising incidence of about 4 per 1000 of the Standard 6 population investigated. Because of this high incidence, and in spite of reservations elaborated in the report itself, I am inclined to attach some weight to the details of the findings reported.

This incidence itself seems to indicate that a fair number of children with epilepsy in ordinary schools are nowadays able to complete their primary education and at least to start a high school education. The incidence found is certainly an underestimation of the actual number.

It is in this report that I find evidence of a higher incidence among Afrikaans-speaking people. Comparing the epileptic group with the universum of all Standard 6 pupils we find: Afrikaans-speaking 72,4%, universum 59,2%; English-speaking 14,1%, universum 30,7%; using both languages 10,0%, universum 6,7%.

When the medium of education is considered, these figures become even more striking. (The medium of education may be taken as the real differentiation between

the 2 language groups.) Then we find: Afrikaans medium 80,5%, universum 60,0%; English medium 17,4%, universum 37,0%.

If this really means that the incidence is higher among the Afrikaans-speaking people (and not an artefact of the investigation and of the pupils' reaction to the question about epilepsy), then this is certainly a very important finding and it should receive due attention, both from the educational and other authorities and from SANEL.

I cannot go into all the details of the other important findings in this report. Some of the more general findings were that they came from the relatively low socio-economic and relatively low educated strata of the community. They tended to come from large families. On mental and scholastic tests they were rated significantly lower than the rest of the Standard 6 population, being about 10 IQ points lower than the average. They were slightly more retarded in the non-verbal parts of the test. Their lower intelligence and lower scholastic achievement were reflected in the Standard 6 examination where, on the average, they had just about reached the limits of their educational progress.

On various measures of personality and adaptation they also compared unfavourably with the universum, but not significantly so, except in certain characteristics, e.g. they showed a higher incidence of sensitivity, tension and irritability; their feelings of personal value were less well developed; they had less awareness of being accepted and recognised, they had less experience of personal freedom and they seemed to be emotionally less stable. One might conclude that at this stage of their development these epileptic children did not show major deviations from the norm but were beginning to develop in a less satisfactory direction.

From our point of view the actual school experience of these children may be more directly relevant. In their attitudes towards school and various school matters they did not show much difference from the others. They quite liked school and the school activities, although they showed less active participation. They had the same hobbies, and one gains the impression that they were fairly well accepted. Nevertheless their teachers seemed to have a rather poor opinion of them. In ratings on their behaviour they were described by their teachers as being: less capable of leadership; poorer in sport; more inclined to truancy; less co-operative towards teachers; less diligent at their schoolwork; and more inclined to conflict with their fellow pupils.

As there did not seem to be sufficient objective grounds for these opinions and attitudes on the part of the teachers, it would seem that teachers find the epileptic pupils somewhat of a nuisance in the academic set-up of a

school and that they might be disinclined to bother much with them.

I have already mentioned that the Standard 6 examination showed that, on the average, these pupils had reached the limits of their scholastic achievement. There would have been quite a number, though, who would have been able to make further progress. On the whole the outlook did not seem very hopeful that any large number of them could complete their high school education. Their teachers thought that 66% of them could never pass Standard 10. Ironically, only 42,9% of the children themselves thought that they were not capable of doing so. This seems to indicate that the majority were at least motivated to try.

In conclusion we may ask what deductions of practical importance can be made from the information available. I wish to enumerate a few which seem to follow from the research reported and from our past experience in this field. A high percentage of pupils with epilepsy can attend the ordinary schools. Control of seizures is satisfactory enough to make this feasible. Whether these schools cater effectively for their educational needs is another matter. Most teachers seem to take a dim view of the epileptic pupil, and there is a need for them to be better informed regarding these pupils and their management. This should be taken care of in their professional training. The specific learning disabilities of pupils with epilepsy are probably insufficiently appreciated and special methods for their remediation are not being used. Teacher training should take note of this. There are not many more pupils qualifying for the existing special schools, in terms of present criteria for admission. We should be careful in increasing these facilities.

Not mentioned in these reports, and not seen in the picture at all, are those children with epilepsy who are severely mentally retarded. Probably our present greatest need is for day and residential centres for their training, or both. Children with epilepsy need much more adequate preparation for life in general to enable them to relate meaningfully to society and to conduct their private lives in such a way that deviations of personality are avoided. The present outlook for employment and financial security is gloomy and much more emphasis should be placed on adequate training in specific work processes which could be put to use in an industrialised country like South Africa.

It seems probable that the incidence of epilepsy is higher among the Afrikaans-speaking White population than among the English-speaking population. This urgently calls for further epidemiological research.

All that has been mentioned in this article applies almost exclusively to Whites. Knowledge of epilepsy in the other races of South Africa is scant, and it is high time that we knew more about it.