

APHASIA — The neglected handicap — The forgotten children

by *Bronwyn Blake*

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The world of the Aphasic child is a strange and confusing one. Imagine yourself wearing earphones, dropped into China, allowed to listen to one or two words per sentence, being told from that to understand the culture and language, learn to speak the language, and educate yourself. This is a milder form of the problem faced by the aphasic child, for unlike the child, the traveller in China already knows the use of language, has a well established internal language albeit in English, and a good background in how cultures operate.

The aphasic child, like his deaf counterpart, faces enormous barriers in his emotional, social and educational life. I would like to elaborate on some of the worse problems with which the family of the aphasic child has to contend. Although the condition known variously as childhood aphasia, congenital aphasia, or language disorder, can be well defined on paper as a condition of severe language disorder with a neurological basis, when presented with the child in actuality the problem appears not quite so simple. Because the incidence of congenital aphasia is low in our community, few professionals have had any contact with the condition, and the parent faced with the problem of the child who does not develop normal communication — language, in its broadest sense — can find herself in severe straits. She is unlikely to have had any contact with this complex problem and is unlikely, unless she is fortunate, to quickly meet with a professional with any modicum of knowledge of the condition. Her own lay diagnosis is likely to foreshadow that of the professional in that the child does not appear deaf, cerebral palsied, mentally retarded, suffering from emotional problems or environmental deprivation. The child is usually one of an ordinary happy family who for some puzzling reason does not ap-

pear to understand speech, does not show any signs of speech or even pre speech, nor does he appear interested in the parents best efforts to interest him in the world of language.

The first problem then faced by the parent is that of diagnosis. It is an unfortunate fact in our community that the local doctor is highly unlikely to have seen an aphasic child before. This in itself would not be such a problem if there was a well integrated and widely known service for the diagnosis of these children.

This however, is not so, and the parent is often fobbed off by the doctor, told to come back in six months; told there is nothing wrong with the child except that the mother is over anxious; or told to go to a paediatrician for further diagnosis. It has been the experience of parents of aphasic children that this seemingly helpful move can be equally unproductive for the child, and even more distressful for the parent. It seems that even amongst paediatricians that the disorder is poorly known, and unless one gravitates to the large Children's Hospitals or services, such as the School Medical Service, one is likely to spend years in the limbo of doctor's offices searching for help. It appears that a conservative estimate of the time taken looking for correct diagnosis of the aphasic child is somewhere in the order to two or three years, and that between five and twenty different agencies can be involved. It is not hard to imagine the stress under which a family is placed during this period; a critical period anyway when the family should be protected from stress where ever possible. One runs the gamut of indignities from abuse — "the mother is unwilling to accept the diagnosis", "she is overwrought and over anxious", "She is shopping around the town", to the absurd — "take the child to a faith healer", "do nothing", "put him in an in-

stitution", "feed him vitamin C". The diagnosis given in the course of these years about a typical child can, for instance, include no problems, mother imagining it, emotional deprivation by parents, untestable deafness (whatever that is!) environmental deprivation, autism, or most frequently mental retardation. Nobody would dispute the fact that these can be valid reasons for the

point with any chance of it being given serious consideration.

It appears currently that unless the parent is fortunate enough to find a knowledgeable professional within her first several visits, the only parent who then survives the system is the well educated, well heeled, English speaking stubborn one. This is totally unacceptable in a multi-faceted society such as ours

aphasic — it would appear reasonable to assume that some form of specific help would be in order and available to both parents and child. One very quickly finds that this is not so. Apart from some small isolated services the whole problem of an early intervention programme and a parent guidance service has been totally ignored by both Health Departments and

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non-appearance of language amongst children, but pity the poor parent with the genuinely aphasic child, attempting to find their way through this jungle of inaccurate description, not knowing much about the condition herself and often not knowing what questions to ask. Frequently all a parent does know is that a particular diagnosis is totally wrong for her child, but without the necessary medical language is unable to even discuss the problem with the doctor, let alone disagree with it and argue her

and only further exacerbates the gaps between the haves and the have nots. Services, and there are several excellent ones in each state, for the diagnosis of language disordered children must be far better co-ordinated between the allied professions, and must be far more widely advertised for both parents searching for the service or professionals needing to refer children to them for further extended diagnosis.

Assume then that the parents have had their child diagnosed as

Education Departments. It appears debatable whether either service or the Ministers responsible for these departments are aware of the condition of congenital aphasia or are aware of the severity of the condition.

It is a terrible indictment of these services, that whilst the deaf, blind, and physically handicapped are catered for with extensive programmes, the aphasiac, or the traditionally “dumb” child is left not only uncatered for, but unrecognised and conveniently ignored.

The young aphasic child, like any other young handicapped child needs a specific early intervention programme particular to the needs provoked by that condition. The parents also need help and assistance in the understanding and handling of these confusing children. Services of this kind are vitally necessary to the family of a young handicapped child if for no other reason than in the prevention of manifold problems appearing at a later age. Parents of any young handicapped child operate under a high level of stress, directly related to their concern about the child; it is hard to imagine a better way to increase that level of stress than to diagnose the problem and then leave the family without any alleviation. I can understand the reluctance of some professionals faced with this official policy of deliberate ignorance, not wishing to diagnose the child in the first place, however it must be realized that personal pressure and the pressures from one's family and society will continue to drive a parent from agency to agency until an accurate diagnosis is effected.

The parent has now been coping with this problem fairly much alone for let us say five years. Kindergarten years have been some relief for the parent if the Kindergarten Teacher was capable and accepting, however the teacher herself has had no recourse to a service, like for instance, Visiting Teachers of the Deaf, and has largely handled the child by guess and intuition.

The child has by now reached school age and the parents face the biggest and worst obstacle in their efforts to assist their aphasic child. With the exception of N.S.W. the educational services for aphasic children in Australia are either grossly inadequate, or as in Victoria at the time of writing totally non-existent.

Official neglect in this area has been so blatant that not even the responsible Minister knows how many of these severely handicapped children exist within his jurisdiction. Extrapolation of figures from an Isle of Wight Study, and a Glasgow study, would indicate probably 600-800 children in Victoria, with a nucleus of 200 of these being profoundly affected. Whether these figures are accurate for Australia remains to be seen. As the lack of statistics seems an insuperable obstacle to some agencies, I suggest one of the first and most practical things we could do to begin to tackle this massive problem is to take an accurate survey to determine the number of children with which we are dealing.

Not only are the services in primary and secondary schools in Victoria totally absent, but we have no teacher training programme to provide teachers if a service were to operate, and no teacher training is envisaged in the near future, despite the fact that several colleges and universities in Australia would be quite capable of mounting a course comparable, for instance, with the one year postgraduate course offered at Reading University, U.K., specifically for teachers of the language disordered child.

It is a bleak picture to compare this situation with the extensive network of day and boarding schools and special language units available in the U.K., and the similar wide range of facilities available for children of all ages in the U.S.A. and Canada.

The aphasic child is faced with several prospects in his attempt to secure an education. He can attend a normal primary school, where the chances of his being able to comprehend the teacher and take any part in classes is at an absolute minimum; he can be placed in a special school, catering primarily for the mentally retarded or emo-

tionally disturbed child., a totally inappropriate placement for an intelligent, well balanced child; or if his parents can afford it he can be placed in one of the rare private schools which will cater for the language disordered child.

The majority of our children of course end up in primary schools where their inabilities quickly make them the class fool and where a history of successive years of failure ends in secondary problems of a type even more severe than the initial language disorder. No teacher, however superhuman, can be expected to cope with a young language disordered child in a class of 25 others where the child has limited language comprehension and a more limited spoken language.

It is totally iniquitous that these children should be condemned at the start of their school life to certain failure, frustration and unemployment, by the total failure of the Education Department to recognise and cater for their most basic educational needs. These are children with active, seeking minds, usually with superb visual memories, often with a compassion and kindness that reaches beyond that of the normal child, and often with an understanding of the ways and relationships of people that would astonish an outsider. These are the children who are being classed in Victoria as not worthy of education, and these are the children whose parents are told they want too much too soon.

Parent groups around Australia have a formidable struggle in their efforts to achieve a barely decent life for their aphasic children. Ministers of the crown and their government agencies have a lot to answer for in their horrific neglect of these children; but the truly sad part is that whilst we battle, the child grows from 3 to 4, to 5, to 6, to 7, and whilst officialdom fiddles our children burn.