TOWARDS INDEPENDENCE THROUGH ASBAH

Margaret and Alan clean their car

Five Oaks

ASBAH has a house in Yorkshire called Five Oaks, which has been specially adapted to make it suitable for handicapped people. It provides holiday facilities, or a refuge in time of family crisis, and it is also home for a small group of young people who for various reasons have no other home. Some of our social independence courses are held at Five Oaks, and a specially designed activities centre is under construction there. A full-time Programme Organizer has been appointed to complement the work of the Head of Home and her staff.

How you can help

All this work calls for large resources. Funds are raised locally and nationally to meet continually increasing demands on the Association's services. A grant from the Department of Health and Social Security is greatly valued, but 93 per cent of the Association's work is financed voluntarily. The problems are immense, and call for support on an increasing scale.

The married couple seen above have spina bifida and hydrocephalus. Other pictures in this leaflet show three young people on an Independence Training Course, and a small resident of Five Oaks. Photos of David, Emma, and Steven by Len Hooper; of Margaret and Alan by Kevin White; of Anne by Jill Vernon.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS
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ASBAH

Emma and friend

What these disabilities are

Spina Bifida is the commonest major disabling abnormality apparent at birth of a child. The words mean split spine, and the openings are called lesions. This condition arises in the very early stages of development, probably even before the mother knows she is pregnant. Its causes are still unknown.

The consequences of the malformation are usually paralysis of the legs, and absence or weakness of control of bladder and bowels. There is no cure yet, but advances in medical science have greatly ameliorated the effects of the less severe lesions, and children are now growing up to take their place in a society steadily becoming more helpful towards disabled people.

Eighty per cent of those with spina bifida also develop hydrocephalus (from the Greek words for water and head) but this condition may occur independently. In 1958 a technique was introduced into Britain for transferring the excess fluid from the head by a valve system into the bloodstream. This dramatically increased the survival rate of handicapped babies, although some of them later find it hard to see in perspective, lack concentration, and have learning difficulties.

Steven ironing

ASBAH's role

Early in the sixties, parents came together to form groups for mutual support and to help handicapped children to lead a full life. There are now more than 80 local associations covering most of England, Wales, and Northern Ireland, and Scotland has its own Association. In each locality meetings are held for the exchange of information and to plan events and projects. Members receive practical and financial help, and local associations raise funds for these ends. From local associations came the idea of a national organization, and ASBAH, the Association for Spina Bifida and Hydrocephalus, was founded in 1966. Its aim is to give all possible support and help to those born with one or both of these disabilities, to their families, and to those who care for them.

Support is channelled through social work and welfare grants, and advice covers a variety of topics: the provision of aids and equipment, accommodation, alterations to the house, education, social development and independence training, leisure, occupation, and employment.

Stress caused by the birth of a severely handicapped child is considerable. There are many hurdles in the life of such a family, for the handicaps of a spina bifida child are multiple. The support of a specialist field worker, particularly in areas where the Social Services are under heavy pressure, does much to help families to cope with strain. The Association has already made 18 such appointments, and further expansion of the scheme is planned. More understanding of a complex set of conditions is greatly needed. Families, young adults, and professional workers now look to the Association for information and advice. A question may remain unasked in the pressure of a hospital visit – sometimes, many questions. ASBAH provides an information service and publishes a range of booklets.

Anne tries the Hoover

Research goes on

Wide-ranging research is in progress, in this country and in many other parts of the world. Recently it has been found possible to detect antenatally severe spina bifida and a related condition, anencephaly, where the brain fails to develop. Provided the parents wish it, the pregnancy may then be terminated. This relieves much anxiety among parents of a spina bifida child who would like to have other babies, for such families run a higher risk than others of a second child with the same deformity. Much better, of course, would be prevention based on knowledge of the causes, and research for these must be and is being extended. Support for research is an important part of the work of ASBAH. A large fund is necessary, with money always available to support without delay any new important project.

Margaret – a housewife