



The Association for Spina Bifida and Hydrocephalus

112 City Road, London EC1V 2ND

AN OUTLINE OF SERVICES AND FACILITIES FOR THOSE WITH SPINA BIFIDA AND HYDROCEPHALUS — ENGLAND AND WALES —

Hospital

Medical Social Worker

Parents of a new born baby with either of the above conditions can obtain both advice and practical help, sometimes including financial help, from the Medical Social Worker at the hospital where their child is treated. Contact with the Medical Social Worker is confidently advised, as her Department will provide continuing support on the occasions when the child attends the clinic or is admitted as an in-patient.

Transport

Transport of a patient to hospital may be arranged either through the hospital or could be asked for through the Medical Officer of Health, as it comes under the Public Health Department.

Fares to Hospital

Assistance with these may be obtained through the Department of Health and Social Security, i.e. for the attendance of a patient. Help with fares when visiting a child in hospital should be discussed with the Medical Social Worker who may have a discretionary fund or who could arrange help through the local ASBAH. Some local Associations have a set sum which may be claimed more or less automatically. Others are willing to receive applications and deal with these according to needs and their resources.

Advice in the Home

The Health Visitor

The Health Visitor is required to make periodic visits to the home of parents of children under the age of 5 and in the case of a handicapped child, her help and advice should be actively sought. Health Visitors are becoming more aware of the problems of Spina Bifida and Hydrocephalus and every effort is being made to see that both they and midwives fully understand these conditions.

Home Adaptation, etc.

Advice regarding allowances, adaptations of the home, etc., may be obtained from the Social Welfare Officer of the Welfare Department of the Local Authority.

(It should be noted that at the present time reorganisation of Local Authorities is taking place and this will mean that there are fewer separate departments to approach, i.e. following the Seebohm Report.)

The provisions of the Chronically Sick And Disabled Persons Act 1970 make adaptation of the home more definitely a statutory responsibility than hitherto. They also include a clause relating to the provision of telephone service.

(It should be noted that where there are "improvements" to a home in these terms, this does not involve a higher rating of the premises.)

Help in the Home

A Home Help may be arranged by the Local Authority in case of need. The General Practitioner or Health Visitor will recommend. The cost of this would be assessed according to means.

Holidays

Assistance towards holidays may be obtained from the local Welfare Department in appropriate cases.

Equipment

Sanitary Aids

Incontinence pads etc., may be supplied by the Public Health Department and in many areas there is a free washing service for non-disposable nappies used by incontinent patients. The Public Health Department also lends nursing equipment.

Incontinence equipment, penile bags or appliances for those with a urinary diversion are on prescription from the Consultant or General Practitioner.

Calipers and Sticks

These are prescribed by the Consultant and supplied by the Department of Health and Social Security.

Boots and Shoes

Are only provided on prescription where none on the market are practicable, when surgical boots are prescribed. Adaptation of normal shoes to take calipers is arranged by the hospital without charge. Further help on footwear may be obtained from the Information Service for the Disabled (see page 7) or from ASBAH, London.

Aids and Gadgets

These may be obtained on loan from the Welfare Department of the Local Authority, where they are not prescribed by the consultant and are needed. Certain play and ancillary aids are often made available by ASBAH Branches to a family, for the period of time needed by a child and are returned for the use of others when out-grown. Other Associations, e.g. the Red Cross, may also assist.

Wheelchairs, etc.

These are normally supplied by the Department of Health and Social Security on a prescription from the Consultant, arrangements being made through the Appliance Officer at the treatment centre. Extras for use in connection with wheelchairs may also be included with the Consultant's recommendation, e.g. hard-based cushions, water-proof cover, leg extensions, removable arms, feeding trays. It is as well to include these at the outset where the needs are known, though they can be applied for later. It is sometimes possible for a second Chair to be prescribed for use, e.g. school or place of work.

Motorised Transport

Three-Wheelers

In approved cases, an "invacar" (three wheeler) is supplied by the Department of Health and Social Security for those over the age of 16.

Other Disabled Drivers

Other disabled drivers may be entitled to a grant towards the cost of adapting a privately-owned car, at present up to £90; no second application for 5 years. In such a case, exemption from Vehicle Excise Duty is granted but insurance is the responsibility of the owner. To qualify for a grant, the hospital consultant first makes a recommendation.

Garage

For the invacar and converted car a garage must be available. Help with this, through the Local Authority (see above) and no enhanced rate payable, is possible.

Parking

The former "yellow badge system" is to be extended under the new Chronically Sick and Disabled Persons Act 1970, which will facilitate parking, both within and outside the area in which the badge is issued.

It should be noted that the badge does not confer any exemption from time limits, etc. Such exemptions will be arranged through the traffic regulations orders under the Road Traffic Regulations Act 1967, etc. The Ministry of Transport is still working on the Disabled Drivers' and Disabled Passengers' badge and full details will be available later.

Education

Pre-School Age

It is the responsibility of the Local Education Committee to provide a service for physically handicapped children from the age of 2, but at the present time there is a great shortage of nursery and play group provision, owing to shortage of money and teachers.

Day Nurseries

These are run by the Department of Public Health (under the Medical Officer of Health) and your Health Visitor will tell you of the nearest. If this is right for your child but there is difficulty in getting a place, the Medical Social Worker at your Hospital may be able to help.

Nursery Schools

These are run by some Local Education Authorities (under the Chief Education Officer). Again there is a shortage, but if there is a problem, it is worth enlisting the help of the Education Office or the Medical Social Worker or your local ASBAH to see if a place can be found for your child. Some special schools (for physically handicapped children) have classes for the under-5's.

The Schools' Medical Officer should be consulted over medical problems in connection with school and the Local Education Authority will advise on transport to and from school, where this is needed.

Pre-School Play Groups/Day Nurseries

These are also run by voluntary organisations—sometimes with Statutory help, e.g. a teacher, etc. Many of the above are run for able-bodied children, but can often accept one or two handicapped children if staff and facilities make it possible.

School Age

The Local Education Authority Schools' Medical Officer is responsible for arranging an assessment for each child, in order to decide, in the light of existing provision, what is the most suitable school considering the aptitudes, ability and medical condition of the child. If your child does not attend any of the pre-school provision above, you should seek assessment for him at least by the age of 3.

The possibilities are (1) Primary followed by Secondary school or by Comprehensive school, (2) Special day school, (3) Special residential school, (4) Home teacher. It should be emphasised that no decision made is one which covers the whole educational life of a child, as both his development and available schools may change and a re-assessment or other plans can then be made.

Further Education

Those who qualify for university, a college of education, etc. will need to seek advice about a college physically suitable to their handicap. The Chronically Sick and Disabled Persons Act 1970 refers to access to school and colleges and this should lead to improvement in existing colleges and full accessibility in new ones.

Employment and Training

Early consultation with the school careers' staff and youth employment officer (specially designated officer for the handicapped in some areas) should be made with regard to courses to follow in school and training to take up on leaving.

There are a number of residential colleges for the disabled, and entry, where suitable, is arranged either by the Local Education Authority or the Department of Employment and Productivity. The latter Department, through the Disabled Resettlement Officer, can also arrange for admission either to an Industrial Rehabilitation Unit, which is chiefly concerned with assessment or to a Government Training Centre.

There is a Register of Disabled Persons, inclusion in which may assist in finding employment. Registration is therefore a wise step.

Some will be able to seek employment in the ordinary way; others may be best suited to work in what is at present known as a "sheltered work-shop", organised by the Department of Employment and Productivity.

Occupational Centres

These are provided for those unable to undertake full-time work and prove helpful. There are also occupational therapy centres; both run by the Local Authority Welfare Department.

Recreation

Some suggestions include:—

Guides and Scouts

These make excellent provision for handicapped young people, either as members of an open company or through special ones. Ask your local Guide or Scout Headquarters, Citizens' Advice Bureau will have the address.

Junior Clubs and the Brigades

These will also offer membership if approached.

Over 13 Youth Clubs

These are run in many areas, called P.H.A.B. Clubs (physically handicapped/able-bodied) so that young people from each group can meet and share recreational interests *together*.

P.H.A.B. Courses

These residential holidays are run all over the country for young people from 15-25. There is also an Over 25 Association. Further details from ASBAH or direct from the National Association of Youth Clubs, 30 Devonshire Street, London, W1N 2AP.

Music For The Disabled

There are Groups meeting regularly and courses are held.

Horse-Riding for the Disabled

The contact is National Equestrian Centre, Stoneleigh, Coventry, CV8 2LR.

Gardening

The Disabled Living Foundation have a leaflet and there is a Permanent Demonstration Garden at Syon Park, Middlesex.

Duke of Edinburgh's Award 14-21

Many handicapped young people have gained much from working for one of the awards—either at school, through a Youth Club or Organisations or even individually. Ask your local Youth Officer or County Association of National Association of Youth Clubs. The Duke of Edinburgh Award Office is at 2 Old Queen Street, S.W.1.

Useful Contacts

The Citizens' Advice Bureau or Civic Information Department in your area will help you over addresses of the Departments referred to in this paper.

The Central Council for the Disabled,

34 Eccleston Square, London, S.W.1.

The Council produce helpful publications.

Disabled Living Foundation

Information Service for the Disabled,

346 Kensington High Street, London, W.14.

Tel: 01-602 2491.

Joint Committee on Mobility for the Disabled,

c/o Spastics Society, 12 Park Crescent, London W1N 4EQ.

The Association for Spina Bifida and Hydrocephalus,

National Office: 112 City Road, London E.C.1V 2ND.

(01-253 2735)

The address of your Local Association can be obtained from the Headquarters or see the Directory in *Link*—ASBAH's magazine.

The Association for Spina Bifida and Hydrocephalus will very gladly amplify on any of the above or assist with the implementation of any section in an individual case. The Association is able to help over the supply of equipment and is prepared to investigate problems.

Local Addresses