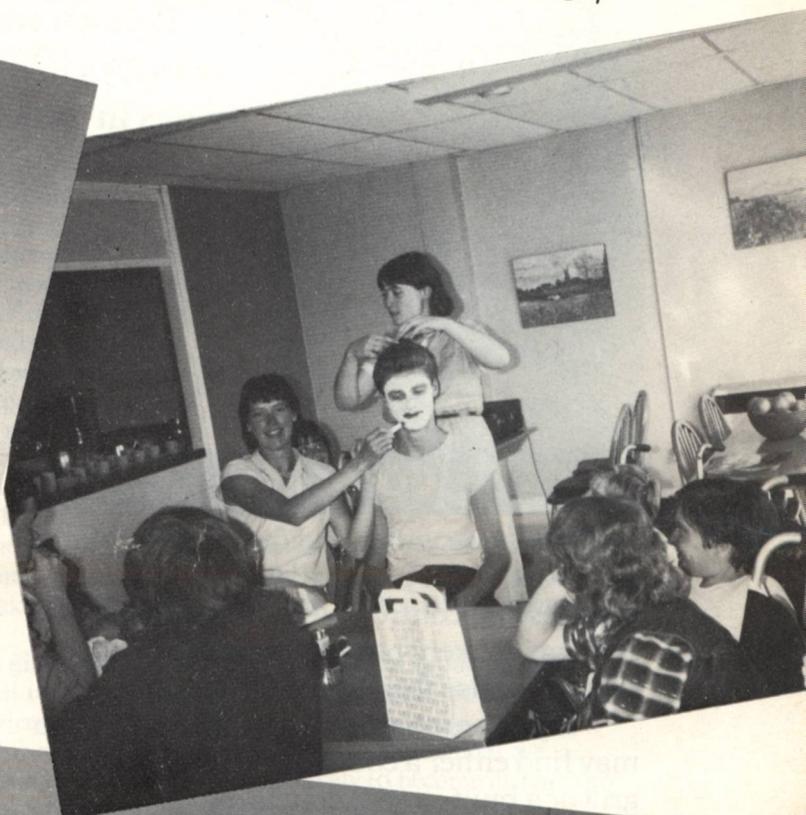




Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

Sept/Oct 84

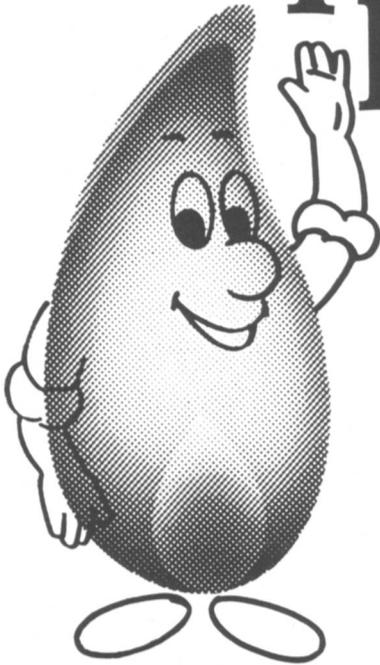


**Epileptic fits: Skiing:
Financial advice:
LIFT roadshows:
Learning 'to let go':
Plus Link Special
Report on Local
Associations**



Front Cover stories page 25

“Help yourself to the help you need.”



British Gas offers a wide range of help to those who need it most — elderly and disabled people.

If you have a disability — or have friends or relatives in need of help — here are some of the ways in which we can make life easier for you.

COOKING

For those with hand disabilities, many gas cookers can be fitted with special handles and controls. And remember, most new gas cookers need no matches to light them, because they have automatic ignition.

If you are confined to a wheelchair, you may find either a cooker with a waist-level grill or a built-in cooker helpful.

For those with failing sight or blindness, special braille thermostats are available for most gas cookers, together with braille cooking charts.

GAS FIRES

Many gas fires are available with easily accessible top controls, to save bending, and most fires light automatically when turned on.

And for those people with hand disabilities, a special tap adaptor may be fitted to a number of fires.

CENTRAL HEATING

Gas central heating needs very little attention and can be set to your own particular pattern of living. Time controls and room thermostats help to save gas and keep running costs down.

PAYING FOR GAS

The Code of Practice for the payment of domestic gas and electricity bills offers advice to customers who are unable to pay their fuel bills because of real hardship. Copies of the Code are available from gas showrooms and local offices, Citizens Advice Bureaux and other advice centres.

If you are blind, severely sick or disabled, you should tell us so that an acceptable method of payment may be agreed with you and so avoid possible disconnection.

Pre-payment gas meters can be re-positioned at a convenient height for disabled people, and special extended handles are available.

HOW TO HELP YOURSELF

Go to your local gas showroom. If you cannot go, contact the Home Service Adviser of your Gas Region, who will be happy to call on you at home and provide advice free of charge. (You'll find the address and telephone number in your local telephone directory under GAS).

MORE HELP

For information about other ways in which we can help — with safety and economy hints, for example, or with a choice of ways in which you can spread the cost of your gas more evenly throughout the year — contact your local Showroom.

BRITISH GAS



Link⁹⁴

Association for Spina Bifida
and Hydrocephalus/ASBAH

Correspondence to ASBAH at the
National Office:

22 Upper Woburn Place,
London WC1H 0EP
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:

HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer: Mr R H Smith

ASBAH has an experienced staff
ready to help with any problems
relating to those with spina bifida
and hydrocephalus.

Executive Director:

Miss M P Gilbertson, MCSP, FBIM

Finance Director:

Mr Derek Knightbridge, FCCA

Appeals Director:

Miss Judy Kay, MIPR

Services Director:

Mrs B Newman

Administrative Assistant:

Paul Dobson, BA (Hons)

Disabled Living Advisers:

Miss Mary Barton, MCSP
Miss Andrea Robinson, RGN, SCM, HV
Miss Mary Small, Dip OT, SROT

Fieldwork Co-ordinator:

Mrs T Cole, MICA

**Accommodation & Development
Officer:**

Ms Siobhan Rowe, BA, Dip HA

**Project Leader at Five
Oaks, Ilkley, Yorks.**

(Tel: 0943 609468):

Mr Jim Stanton

Information Officer:

Miss B Holland

Link Editor:

Mrs Susan Gearing

LIFT (Young ASBAH) Organisers:

Paul Cooper, BA (Hons)

Vivian Harper, BSc

Mobility and Independence

by MRS LYNDA CHALKER, MP, Minister of State for Transport

THE GREATEST handicap facing many disabled people is not their own physical difficulties but the obstacles and barriers which surround them. Transport — or the lack of it — can be one of the biggest barriers. So I would like, in this column, to offer a few thoughts from my own personal experience over many years of working with and for disabled people and from my particular ministerial responsibility for the transport needs of disabled people.

For many people disability comes late in life at a time when the desire, and indeed the ability to travel may be reduced simply by age. But for those young people who are growing up with disabilities what prospects and opportunities can they expect?

In the public transport scene enormous progress is being made — although to anyone trying to move about the public transport system in a wheelchair, the gaps and shortcomings are still only too painfully apparent! But it is now possible to travel inter-city by train in your wheelchair, not in the guardsvan but in a first-class compartment — and for half a second class fare. Facilities at stations too are improving fast and BR are committed to providing total access to a core network of main line stations by the end of 1984.

More and more bus and coach operators too are now starting to provide better facilities both for ambulant and wheelchair bound disabled people — and are beginning to find out that very often what makes life better for a disabled traveller makes it better for everyone else too.

The rapid rise in dial-a-ride services has also brought about a marked change over the past two or three years. Over 150 of these special door-to-door transport services, mostly using lift equipped minibuses, are now operating up and down the country, and as we learn more about the economics of operating such services they are likely to become increasingly firmly established as a part of the transport scene for disabled people.

For those living in London and other big cities the new generation of 'London' taxis — due on the road from next year — should help solve a great many problems and, in particular, the constant anxiety about interchange — getting from one station to another, or from home to the bus station or airport.

Of course, in terms of total independence, there is no substitute for having your own car. Here again both the technology of vehicle design and the



MRS LYNDA CHALKER

Continued on Page 9

Pages	CONTENTS
4	News 21
6	Round-up 21
7	Holiday Competition 22
8/9	Epileptic fits 24/25
10/11	Skiing for the disabled 26
13/19	LINK Special Report on Local Associations 27
	Financial advice for the children's future 28
	LIFT roadshows 28
	Learning 'to let go' 28
	Appeals 28
	Classified Advertising 28
	Directory of Local Associations 28

While every care is taken to ensure accuracy of information published in LINK the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH.

The Battle for VAT relief continues

RADAR will continue to campaign for VAT relief on house adaptations needed by disabled people. An amendment to the Finance Bill, which would have given this relief, was defeated in the House of Commons despite being supported by members of all parties.

'This battle must be continued' said George Wilson, Director of RADAR. 'House adaptations are carried out because disabled people need them not just because of personal choice . . .'

Although there is a limited range of adaptations that will be zero-rated for VAT, RADAR believes that this concession is much too restricted and will cause confusion. George Wilson added 'We believe that the Treasury has not realised the implications of its action over this. We will be working to persuade them that zero-rated house adaptations that have to be carried out for disabled people is not only just but also sensible administration.'

Benefits service goes nationwide

BENEFITS Information Service is a new group which aims to bring together the sources of information on welfare benefits to provide a service for statutory and voluntary agencies nationwide.

'Benefits Briefing' is the first of its productions. It is a fortnightly information service on all aspects of social security. It contains parliamentary briefing, new legislation, new publications, jobs and noticeboard section.

Further information from: Benefits Information Service, 10a South Road, West Bridgford, Nottinghamshire NG2 7AG. Tel: 0602 819823 (evenings only).

Car Insurance problem

PARENTS of children in receipt of Mobility Allowance can apply for road tax exemption by having their car registered in their child's name. It appears, however, that some parents are finding it difficult to obtain insurance cover because the child's name appears on the logbook. Anyone faced with this problem should point out to the insurance company that the child is, in fact, the registered keeper of the car, and that ownership remains with the parent. A phone call to the DVLC in Swansea will confirm this if an insurance company remains doubtful.

NAIDEX goes to Warwickshire

STONELEIGH, Warwickshire is the venue for this year's NAIDEX (International Aids for the Disabled Exhibition). It will be held at the Royal Show Ground, National Agriculture Centre on October 10, 11, 12 and 13. Admission will be free. Wednesday October 10 is for professionals only, and Saturday 13 is for the disabled and their families/friends.

Supakart owners get into gear

THE YOUNG DISABLED MOBILITY CLUB was formed in June this year — initially for young Supakart owners in the Middlesex area — but hopefully it will go national.

So far it has 40 members. T shirts are available and rallies are being organised for the members. If these prove successful Mr Jimmy Wright, OBE the founder, hopes there could be national rallies.

Mr Wright is actively concerned with disabled children and has purchased many supakarts for disabled youngsters through the Spelthorne Integration Group (formed as a support committee for IYDP) and with the help of many local clubs, youth organisations, and special events.

"Two year ago we founded the Spelthorne Speedwell Supakart Club and held what we thought may have been the first ever outdoor rally for Supakart owners in Shepperton. This was a great success and we followed it up with another last year," he said.

The Young Disabled Mobility Club will hopefully widen the activities of this initial Supakart Club.

T shirts are available for any Supakart owner, wherever they live. Three sizes — small, medium and large — with lettering in black on white 'Young Disabled Mobility Club', price £4 each.

T shirts and more details from Mr Jimmy Wright, 209 Manygate Lane, Shepperton, Middlesex TW17 9ER.

SHASBAH TROLLEYS

The proven and established aid specifically made for spina bifida children. Made by those who know and care — spina bifida adults.



- Solid construction
- Easy to manoeuvre
- Finished in brilliant poppy red
- Two standard sizes
- For children 2-7 years

Special models to suit personal requirements made to order. Also available through DHSS.

ENGRAVING

- We also undertake the engraving of:*
- ★ Signs, notices
 - ★ Instructions
 - ★ Name plates on plastic or metal

LET US
QUOTE
FOR YOU

COURT ENTERPRISES
14 COURT ROAD,
SPARKHILL,
BIRMINGHAM B11 4LX.
TEL: 021-771 0380

Court Enterprises is a sheltered workshop for people with spina bifida.

A new benefit for some long-term sick and disabled people.

From November 29th 1984 some long-term sick and disabled people will be able to claim a new benefit if they are unable to work and don't qualify for Sickness or Invalidity Benefit.

The new benefit is called Severe Disablement Allowance (SDA for short), and will be worth £21.50 a week, tax free. It does not depend on National Insurance contributions, and doesn't involve a means test.

SDA replaces Non-Contributory Invalidity Pension (NCIP) and Housewives' Non-Contributory Invalidity Pension (HNCIP).

Everyone who already gets NCIP or HNCIP will be transferred to SDA automatically in November 1984.

The main difference between SDA and the present benefits is that married

women will be able to claim SDA even if they are able to carry out normal household duties.

People who have been incapable of work since before their 20th birthday can qualify for SDA simply on that basis. Those who become incapable of work later in life must also be severely disabled to qualify.

People aged 50 or over and those aged 16 to 34 can get SDA from November 1984.

Those aged 35 to 49 cannot get SDA until November 1985, but should claim NCIP or HNCIP before 29th November if they are eligible.

To find out more just send the coupon to: DHSS Leaflets Unit, P.O. Box 21, Stanmore, Middlesex HA7 1AY.

Please send me the explanatory leaflet and claim form for:

Severe Disablement Allowance NCIP HNCIP Tick the one(s) you want.
(Please allow 21 days for delivery.)

Name _____

Address _____

_____ L1 Postcode _____

Ceris Owen, a teacher at Dorin Park School, Upton, Chester has written especially for LINK, an account of their recent school French camp.

Camping in France proves a success

AFTER nearly twelve months preparation, planning and fund-raising our day of departure for our first continental camp to Northern Brittany had arrived.

Although the drive from Chester to Portsmouth was a long one the journey passed quickly. The night crossing to St. Malo aroused much excitement and anticipation.

The actual camp had been organised through Eurocamp Ltd. of Knutsford and their chosen site at Perros Gairree, 80 miles from St. Malo was an idyllic coastal setting. All of the facilities at the site were excellent and the ready erected tents proved to be ideal for wheelchair access.

Having got over the long journey surprisingly quickly, all the pupils were eager to explore the local beaches and nearby villages. The actual positioning of the site proved to be central for visiting Lannion, Tregastel, Treguier and Port Blanc. Owing to the excellent recreational facilities on the site it was possible to spend every other day based on the actual camp site.

The day of departure arrived far too soon and as we organised our homeward journey there were many sad, well-tanned faces on the night crossing from Roscoff to Plymouth.

All the staff and pupils realise that such ventures as this would be impossible if it was not for the financial support that was so readily provided by the Chester Branch of ASBAH. On behalf of everyone may I say a big 'Thank you'.

Bill's loss is Association's gain

HERTS and South Beds Association is 'heavier' by over £100 thanks to Bill Percival who went on a diet for the local association and is now lighter by 2½ stone.

Bill said: "I had tried to lose weight before but always gave up. So this time I decided to commit myself in some way so that someone else would benefit from my weight loss as well as me."

LIFT plans another weekend

FOLLOWING the very successful first ever LIFT weekend this year, a second one is planned for 1985 — International Youth Year. This is to be held at the same venue, Owens Park, Manchester, March 29-31. Contact the LIFT office if you would like more details which should be available before too long.

Treasure Hunt starts here

ASBAH will benefit from an exciting transatlantic Treasure Hunt which is now getting underway.

To join the hunt, treasure seekers must buy a copy of 'The Last Fairy' by Fred Hancock. The text and pictures contain clues as to the whereabouts of the treasure. Wonderful Wizard Kitwillies Magic Wand, fashioned in 18ct gold and inlaid with diamonds is buried in the UK. Find that and you travel free to the USA to find the Gold Fairy. And that's not all — the final secret is then revealed and the greatest treasure of them all is yours — worth £25,000.

The Magic Wand, the Gold Fairy and the final treasure are all replicas of King John's treasure that was lost in the Wash hundreds of years ago.

The author, Fred Hancock, is the only person who knows where the treasure is buried. Precautions are being taken to prevent the digging up of private property, which has caused problems with previous treasure hunts.

The treasure is buried in common land, and treasure hunters are asked to pinpoint it on an ordnance survey map with a 6 figure grid reference. If this is correct the author will give them the O.K. to go ahead and dig in that spot.

ASBAH benefits greatly from every copy it sells.

If you would like 'The Last Fairy' send £5.25 (to include p & p) to: Hazel Berrow, ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

New Protectapatch replaces Stayflex

RECENTLY ASBAH's Disabled Living Advisers have had several letters requesting 'Stayflex', the iron-on material which was used to reinforce areas of clothing which had to withstand excessive rubbing and wear and tear.

ASBAH bought the last few bales of 'Stayflex' from the manufacturers when they ceased its production a few years ago. We then supplied pieces of material on request and now have only a few lengths left.

There is now another company supplying a similar white material. This is made in the USA and called 'Protectapatch'.

It is a specially formulated non-woven polyurethane that melts into fabric when ironed on, coating each individual thread thus prolonging the life of the garment.

Price 50p each patch, or £2.50 for a pack of six (plus postage).

Details: Artimaze Ltd., 118 Wood Lane, London, NW9 7LX. Tel: 01-450 9588.

Large nappies: are they available?

ASBAH is currently trying to find out which social service departments are providing larger size nappies to older children.

Mary Small, one of ASBAH's Disabled Living Advisers comments: "These larger nappies are on the market — from Peaudouce (Slipad) and Ancilla. You should be able to get these through the Department of Health, but we don't yet know in practice which areas are supplying these."

She suggests that you ask for these nappies, and if the answer is 'no', don't give in but put up a fight.

Mrs E. I. McDowell, Secretary of the Northern Ireland ASBAH, has written to say that this is an area which is concerning her, too, and she — like Mary Small — would be pleased to hear from any parent who has been successful in obtaining a larger size nappy through the social services.

Mary Small is at ASBAH National Office, and Mrs E. M. McDowell, at 23 Dalboyne Park, Lisburn, BT28 3BU, Co. Antrim (Tel: Lisburn 6023).

Win a free dream holiday

HERE is a second and last chance to enter the exciting competition exclusive to LINK readers to win a holiday at Skylarks, the Winged Fellowship hotel in Nottinghamshire.

The competition was featured in the last LINK and is sponsored by Peadouce, makers of Slipad. Unfortunately, response has been very slow — perhaps because of the holiday period — so Peadouce have

extended the competition to Wednesday, October 17.

The winner will receive a two-week holiday for one at Skylarks Hotel worth £300 and a case of Slipad. The holiday will have to be taken later than originally planned and this will have to be agreed with the winner.

For full details about the holiday prize and about Slipad see the last issue of LINK (page 10).

HOW TO ENTER

ALL you have to do is answer these four questions (underline your choice):—

1. Which of these five cities is the capital of Canada:—
Dallas, Lisbon, Washington, Ottawa, Toronto
2. Which of the following resorts is on the Mediterranean:—
New Orleans, Wellington, Nice, Baghdad
3. In which of the following six countries would you expect to eat Spaghetti:—
Poland, France, Italy, Spain, Morocco
4. In which of the following six countries would you expect to find the Grand Canyon:—
Greece, Monaco, United States of America, Saudi Arabia, India, Czechoslovakia.

Then, in not more than 15 words, tell us why you would like to win this holiday

NAME (in full)
 ADDRESS
 TELEPHONE NUMBER
 AGE HIP MEASUREMENT

Please send your entries to:—
 Peadouce/Spina Bifida competition, Peadouce (UK) Ltd, Rye Road, Hoddesdon, Herts.
 The competition is open to residents in the U.K. only.



National Aids for the Disabled Exhibition

Sponsored by RADAR and Macmillan Journals Limited

FREE ADMISSION
 FREE PARKING



National Agricultural Centre Stoneleigh, Kenilworth, Warwickshire 10, 11, 12, 13 October, 1984

- Aids for daily living
- Bathroom/toilet furnishings
- Body supports
- Communications
- Handicrafts and toys
- Kitchen equipment
- Physiotherapy exercise equipment
- Rehabilitation aids
- Stair lifts and hoists
- Vehicles and accessories
- Wheelchairs
- Information and services
- Nursing Homes and Rest Homes Equipment

Exhibition details now available from
Naidex Conventions Limited
 Convex House 43 Dudley Road
 Tunbridge Wells Kent TN1 1LE
 Telephone 0892 44027 Telex 95604 MEPNCL

For information on low cost rail travel
 please contact Naidex Conventions Limited

OUR BRAINS consist of millions of nerve cells connected with each other in a complex network like a vast telephone exchange. These cells have a minute electrical charge which even when we are asleep gently varies like the waves of a calm sea. These are literally our brain waves and the gently waves are called an alpha rhythm.

Storms in our brain waves can occur and can produce fits or seizures. People who have a tendency to repeated fits have epilepsy: they are epileptic people.

What is a Fit Like?

Anything which upsets the calm sea of our brain waves can result in a fit:

“He fell to the ground and began to shake and twitch uncontrollably — seemed to have trouble breathing and became pale and clammy.

After about two minutes the shaking ceased and he came round, but was a bit confused.

Before the fit he was acting quite normally — but suddenly cried out and the fit began.”

Other fits can be much shorter — just a single jerk or a few seconds when “she wasn’t with us, and didn’t seem to hear what I said”. These short fits can occur without the person falling to the ground but they do interrupt life or school work and may disturb the persons concentration for a whole day.

In some people fits occur at particular times of day: when waking up, is fairly common or when hungry and this can be very useful when planning ways to avoid fits or when advising on drug treatment.

What Causes a Fit?

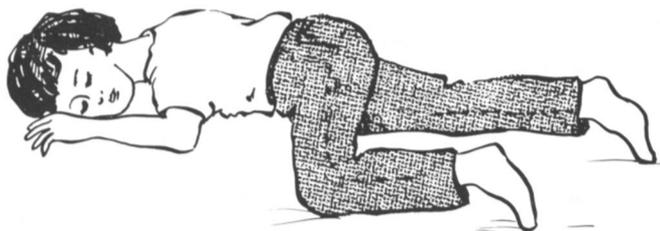
Anything which disturbs the brain cells can cause a fit. One in 200 of all people have epilepsy. One in 20 toddlers have a fit with fever but do not have fits later and are not epileptics. They have febrile convulsions, sometimes wrongly called teething convulsions, well at least they are not caused by teething.

Quite a lot of people have a fit when they stare at a flickering light especially a flickering fluorescent strip light or faulty TV set; more rarely Disco lights will do it if you stare at them.

Hydrocephalus is a physical disturbance to the brain. A shunt or drain put in to relieve hydrocephalus is another disturbance to the brain however necessary the shunt is to prevent damage from the hydrocephalus. So people with hydrocephalus are more prone to have epilepsy.

The Effects of Fits

Fits are frightening. Almost everyone who sees a person with a fit, most particularly a child, thinks they are dying. The dangerous situation comes about through inhaling food so put the person in this position



and lift the chin with your fingers to help breathing. It is

Epilepsy: cause effects and treatment

not necessary to put anything in the mouth, the tongue will fall forward in this position anyway. If the fit continues, get the person to a doctor or give the emergency drug treatment by injection or by the rectal route if that is what you have been shown.

Frequent fits harm brain cells and dull the persons school work or alertness generally. That is more harmful than the proper dose of an anti-convulsant drug can ever be.

Fits when they begin may be a sign of:

- a blocked shunt
- infection of the brain (meningitis or ventriculitis).

There will almost always be other ways of knowing this, such as unexplained vomiting, headache or increasing drowsiness. But medical examination is very important and may be urgent.

How are Fits Investigated?

(Notes for patients)

1. By medical examination, for example, looking in the eyes with an ophthalmoscope, and checking the valve/shunt if they patient has one.
2. By EEG (Electroencephalogram)



It is like wearing a bathing cap with wires on — *no* needles and *no* electric shocks. It is your electricity they are measuring and they can’t tell what you are thinking either.

3. By X-rays including computerised X-ray (C.T. scan/EMI scan). This is like putting ones head in a washing machine which is *NOT* turned on: boring but painless. It gives pictures of the ventricles.

How is Epilepsy Treated?

If there is an acute upset this will need putting right — the treatment of meningitis for example or shunt revision.

It may be possible to avoid some situations which produce fits in someone who is epileptic. For example, a

biscuit and milk before getting up in the morning if hunger is causing fits first thing may be the answer. Or, get the TV fixed.

By drugs. The right dose of the right anticonvulsant drug is very important. No two people are the same. Different drugs work for different people. There are at least a dozen in regular use. Large people need more than small ones.

BUT the handling of drugs (metabolism) varies between people so it is likely that a blood test will be useful to see what the blood level of anticonvulsant is. The dose is then adjusted up or down very gradually as necessary.

One last point is that a sudden change in drug dose is

usually bad. It is a dreadful bore taking tablets and medicine can be worse but if the patient suddenly stops taking an anticonvulsant it makes fits very likely.

Some very useful pamphlets for people with fits, their parents or teachers are produced by —

National Society for Epilepsy,
Chalfont St. Peter
Gerrards Cross,
Bucks, SL9 0RJ

by

JOHN KEEN

Consultant Paediatrician Booth Hall Children's Hospital, Manchester and a member of ASBAH's Medical Committee

People in search of contacts

THE following people have asked for their names to be mentioned in LINK, as they would like readers to contact them.

Mrs D. Kimpton, Egypt Cottage, Baring Road, Cowes, Isle of Wight, PO31 8DL. She is writing a book to help parents of handicapped children cope with their emotional difficulties. It is to be based on the practical experiences of parents — she herself has two handicapped youngsters, and she would like to hear from parents including those who have found they could not cope, or whose child has died.

Mrs Audrey Copeland, 150 Brockley Rise, London SE23 1NW. She would like to hear from older people with congenital or acquired hydrocephalus. Mrs Copeland, in her early 50's, was diagnosed two years ago as having hydrocephalus, although her doctors say she probably had it from birth. She feels very isolated and would like to be put in contact with other older adults with hydrocephalus especially in her own area.

Miss V. Slane, 2 Maitland House, Church Gardens, SW1. Miss Slane has hydrocephalus and is registered blind and physically disabled. She is proposing to start a tape magazine for people who are visually handicapped and also have an additional disability such as spina bifida. Could anyone interested (over 18 years) write to her in braille, or by tape.



● Above — the prototype of the new London taxi.

● Right — Strathclyde's accessible bus.



Opinion: Continued from page 3

opportunities for learning to drive are opening up fast.

For several years now it has been possible for a young person receiving Mobility Allowance to apply for a provisional licence at 16 instead of the normal age of 17. This change was made in recognition of the vital importance of mobility to disabled school-leavers looking for work or hoping for further education.

One of the biggest obstacles has always been the chicken and egg problem of not being able to find out if you are likely to be able to drive, and if so what type of car and adaptation you might need, before actually committing yourself to buying a car because there is no other means to learn.

One way in which my Department is helping to overcome this problem is through a booklet — to be published shortly — giving information and guidance on the particular features to look out for — and indeed to avoid — in choosing a car if you have a particular type of disability or physical limitation.

Of course, there is really no substitute for trying it out for yourself and here, too, the Department of Transport has been trying to help. I hope that many of you will have had the opportunity to visit last year's Mobility Road Show at Crowthorne in Berkshire. Nearly 10,000 disabled people came to the show over three days and were able not only to look at a wide range of cars and adaptations but actually to test drive them around a road circuit with expert guidance on hand from driving examiners. The same opportunity will be provided at next year's Mobility Road Show to be held on 13, 14 and 15 June 1985 at the Transport and Road Research Laboratory. Everyone is welcome and all those with full or provisional licences can test drive cars of their choice. (For further details about the Mobility Road Show contact the Department of Transport, Room S13/09, 2 Marsham Street, London SW1, or phone 01-212 5257.)

All in all, the transport scene is opening up and improving for disabled people — both in public transport and private motoring. So why not see what is available which might help you to be more independent. There could be more going on than you think.



Waiting for their ski bus. Brian Goodwill, who has spina bifida, is second from the right.



Jonathan on the final sections of the slalom. He uses one stick. As a result of cerebral palsy he has hemiplegia. Keith, the chief instructor, is in the background.

A SKI instructor leading four pupils down a blue run is not an uncommon sight in Austria. This, however, is an uncommon group. The pupils are disabled.

The first two skiers, Karen and Peter, employ ordinary snow-plough turns to descend; Jane with the help of her outriggers skis parallel and Jonathan throws the odd 360° turn into his repertoire of linked snow-plough turns.

As a result of Jonathan's cerebral palsy one leg is stronger than the other and the stronger leg occasionally pushes him full circle. Karen and Peter suffer from epilepsy and Jane from leg and feet disability as a result of an accident.

The instructor and pupils are enjoying a weeks skiing in St Johann, Austria organised by "The Uphill Ski Club of Great Britain". The party included twenty-three skiers with a variety of disabilities, including spina bifida, fourteen helpers, including a number of medical personnel and five instructors, four of whom were on an unpaid holiday from the Cairngorms.

Many non-handicapped people regard skiing as an exclusive sport which is both difficult to master and a mite dangerous. How then can the disabled expect to enjoy it? The answer is twofold; firstly the participants require tons of spunk and secondly ingenuity is required in the design of the equipment.

The basic skiing aid is the outrigger. The outrigger is simply a crutch with a short ski on the end, it is held in the hand and supported on

Disabled Skiers do it Uphill

by
Phillip O'Brien

the forearm and is used by anyone with a leg or foot handicap. Skiing relies on leg co-ordination, therefore those that lack this must rely on other limbs to overcome the handicap and the outrigger enables the use of the arms.

Another adaptation is the steer-ski which consists of a pair of handlebars attached by a pole to a short ski. Like the outrigger the steer-ski gives the skier an additional point of balance and it allows the arms to assist in stabilising and steering.

A very simple adaption is to tie the ski tips with a piece of cord. This means ski tips cannot move more than 6"-9" apart. The idea is to prevent the skis from wandering apart. It also made the basic plough position easier to achieve.

A specially designed sledge, a bath-like creation on skis and a ski-bob were also available for use.

These aids were invaluable to the handicapped skier but they did not make skiing easy: they only made it possible. The outrigger especially

takes a deal of mastering as I know from attempts at using it.

These aids may be invaluable but they are not miraculous, and they did fail to meet the requirements of some holidaymakers. For Keith, the chief instructor, this was one of the frustrating aspects of the holiday. People with a real aptitude for skiing were prevented, by the extent of their disability or the lack of suitable equipment, from expressing their talent. He hoped new ideas in equipment design would help to overcome certain problems.

On the first morning the helpers were stunned at how quickly the holidaymakers learned to ski. The lingering memory of that morning, besides the peels of laughter, was the quiet persistency shown by most of the skiers. No matter how many times they fell it was up and on with the skiing. The desire and determination to learn was tremendous but so was the sense of fun.

The instructors divided and redivided the party according to ability and by Tuesday there were four groups. From the party of twenty-three aspiring skiers four had graduated to bashing blue runs, a further eight had mastered stopping and turning at will on the nursery slopes.

Some of the skiers in groups two and three could certainly have managed something between the nursery slopes and a blue run but there was nothing quite suitable at the resort. Eight had mastered skiing in a straight line, but not always in the direction they were facing, sometimes it was backwards, and



Joanne, with spasticity in the legs, demonstrates how to use the outriggers.



At the end of the week the prize-giving ceremony recognised a number of different qualities. Terry earned his award as 'Personality of the Week'.

they could not always stop or turn at will.

There were three people who did not manage to ski independently. Matthew gained great pleasure from the ski-bob and although he would have preferred to ski he was happy with a very good second best. He certainly managed far greater speed, control and independence with the ski-bob than he had on skis.

The sledge is the last option but despite enjoying it there was no hiding the fact Terry wanted to ski. The sledge, however, gave him the satisfaction of coming down the slope unaided and also the thrill of speed with control.

Paul suffered severe pain in his hands with any aid that was tried with him. He was disappointed and as an experienced sailor had hoped to cope well with skiing. Disappointed he may have been, depressed he was not and he contented himself with sun-bathing and vigorous après skiing.

The week's skiing culminated in a race on Friday morning, in fancy dress. All the skiers had the opportunity to race through a slalom course. Two declined, a few through race nerves skied well below their best, others excelled.

The friendliness and help of the Austrian community and the hotel staff made the skiers feel welcome.

All in all, it was a memorable holiday for skier, instructor and helper alike. It was not a token skiing holiday, the opportunity to learn was real. The instructors took the skiers' progress very seriously and awards of merit were only given

when they were strictly deserved.

What is important is that opportunities do exist for the disabled to become good skiers.

For Jane, an experienced skier before the accident that disabled her, the holiday provided the opportunity to re-learn a sport she loved.

"Suddenly instead of being told what I couldn't do I was amongst a crowd of people who were prepared to aid and abet me in doing something that most people would consider ludicrous for a disabled person."

For Terry the holiday was "... a dream come true, marvellous, fantastic, wonderful fresh air, beautiful scenery", Terry had the same gushing enthusiasm throughout the holiday.

For John the holiday was "... a terrific boost to my morale ... a real uplift ...".

Everyone gained great pleasure from mastering a new technique especially one which is widely regarded as glamorous, difficult and dangerous. For some the thrill of skiing was central to the holiday, for others having a good time off and on the slopes was the plan.

One common factor among all the skiers was their almost matter-of-fact approach to skiing. They were excited by it but not over-awed by the difficulties, they simply got on with it. After all, struggling to balance was an everyday effort for many, skiing was only a little more difficult than climbing stairs or negotiating furniture, it was definitely, however, much more fun.

I will conclude with the words of

Dr. David Morris, founder of The Uphill Ski Club. "This venture is therapy in the true and full meaning of the word. By enabling these young people to do undreamt of things we are contributing richly to their characters and personalities." I would add that as a helper privileged to observe the incredible efforts of these skiers they have contributed richly to my life.

The Uphill Ski Club is a registered charity (charity number 287106). Further information can be obtained from:— The Uphill Ski Club, 12 Park Crescent, London W1N 4EQ.

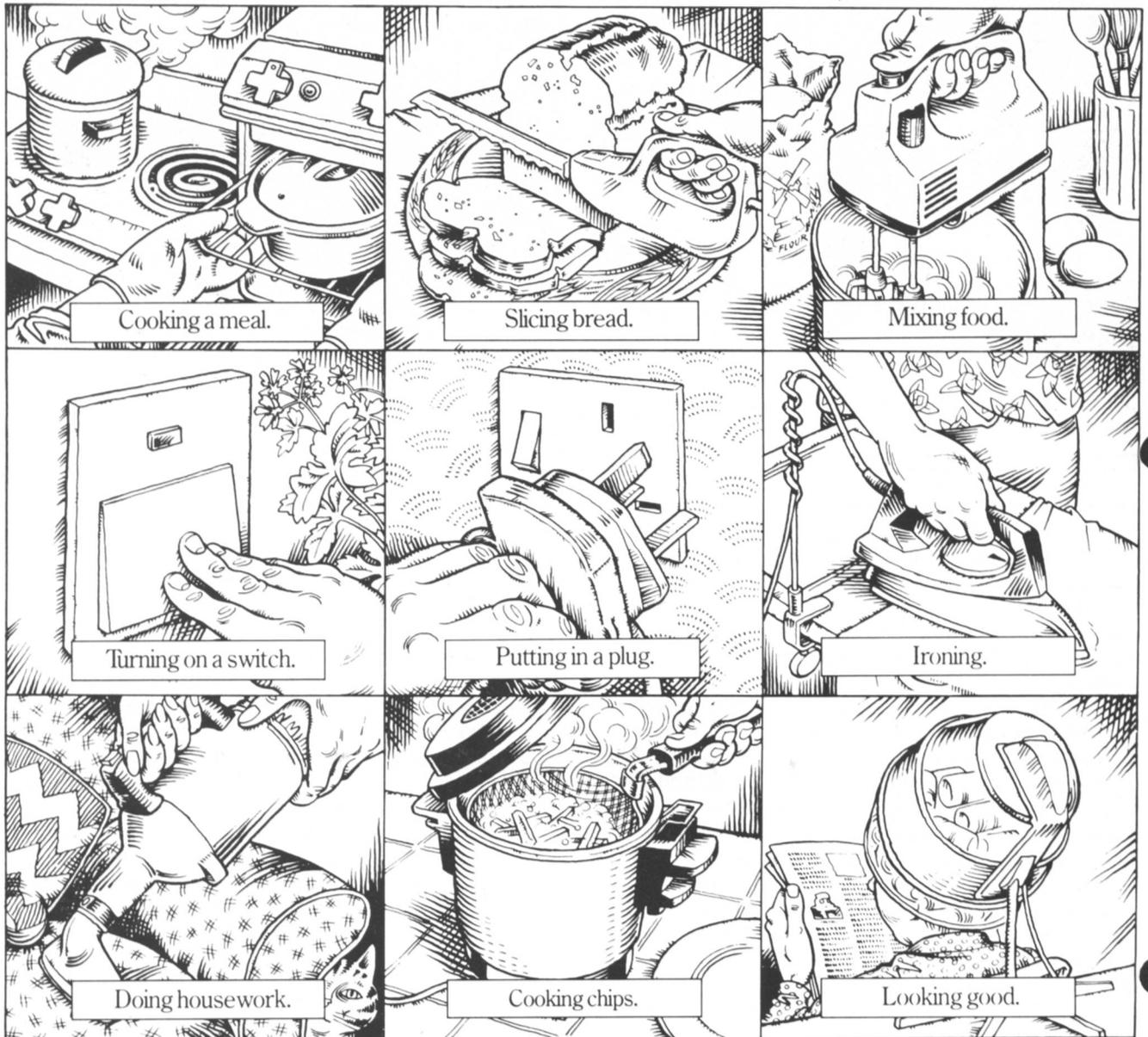
Mr J. Egar, MBE

Northern Ireland Association for Spina Bifida and Hydrocephalus

THE MEMBERS of the Northern Ireland Association very much regret the death of the Honorary Treasurer, Mr J. J. Egar, MBE. Mr Egar was one of the founder members of ASBAH in Northern Ireland and served for many years in the roles of Chairman, Hon. Secretary and in later years Hon. Treasurer.

Despite very poor health in recent years, Mr Egar fought wholeheartedly on behalf of disabled people in our province. Northern Ireland Association has lost not only a most valuable worker but a sincere friend.

For many years Mr Egar was a regular attender at ASBAH Council and made a very significant contribution towards establishing firm links with Northern Ireland.



Is it this easy in your home?

At your Electricity Board, we have a leaflet called "Making Life Easier for Disabled People".

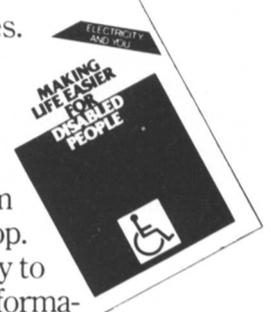
It contains lots of helpful ideas and lists many electrical appliances which can make life easier.

Appliances such as table-top mini cookers. Electric knives which require only a slight pressure to operate. And small, hand-held vacuum cleaners which can be used for dusting, too.

The leaflet also gives details of brailled controls that can be fitted to

certain electrical appliances. And specially designed attachments for plugs and switches which afford easier handling.

The leaflet is free, from your Electricity Board shop. Or you can write for a copy to the Electricity Council, Information Centre, 30 Millbank, London SW1P 4RD.



THINKELECTRIC

The Electricity Council, England and Wales.

Special Report on Local Associations

18 years on — what the Local Associations are doing

In some areas the role of the fieldworkers, financed jointly by local associations and national ASBAH, has proved of immense value in sorting out problems and giving support to individual families. The associations have a responsibility to give help and support, as is needed and practical, to anyone in their area with spina

bifida and/or hydrocephalus, whether or not they are officially 'members'.

Some of the larger associations have gone forward and become less 'amateur' getting involved in big projects like the building of the Spina Bifida Unit at Frenchay Hospital, Bristol, the workshop in Birmingham, the flats scheme in Southampton.

The main problem facing many associations is lack of response by members and the shouldering of duties by the same few people, who because they are usually parents of spina bifida youngsters, have very little spare time.

Some groups have managed to break out of this by involving more 'outsiders' as members. Others have taken on paid secretarial help and special premises. Many have found the value of linking with other local organisations for the disabled.

By becoming outward-looking, part of the community and getting to know who pulls the strings, as well as by pooling resources with other bodies, associations have found they can move forward and provide a better service and have a viable future.

The growing participation in the running of the local associations by spina bifida members is greatly welcomed, as is the formation of 'young ASBAH' — LIFT — groups.

National ASBAH tries to be of as much practical help as possible to the local associations, providing information, advice, and where necessary, financial help. Keeping in touch with members locally — by travelling around, going to meetings, attending special ASBAH workshops, and through the Spring Conference — is an exceedingly important part of the work of National ASBAH staff.

Most local associations are affiliated to ASBAH and all of these have the right to take an active part in the affairs of the Association by virtue of their representation on Council from which the Executive Committee is drawn.

IN THIS 18th birthday year of ASBAH, LINK looks at the work of the local associations spread through the UK. There are over 90 of them. It carries 'mini reports' taken from letters sent in by 27 of the associations for this magazine Special, highlighting some of their many activities and projects.

The local associations were formed as self-help groups for families with spina bifida children. The linking of families in this way and the social support and friendship this engenders is still the main value for many of them today.

The groups provide practical help and an information service — many of them send out their own newsletters. Most associations have bought their own special holiday caravan, chalet or bungalow. Fund raising takes up much of their time and energy.



Bevois Mews — special flats built by Southampton and Swaythling Housing Association.

Southampton

THE GREAT achievement of Southampton local association is Bevois Mews, special adapted flats for disabled people.

The flats were built as a result of a partnership between Southampton association and Swaythling Housing Association and consist of five self-contained ground-floor flats, a community lounge and utility room. First floor flats will be let by the Housing Society to able-bodied or the ambulant disabled and Southampton association is nominating people for the ground floor accommodation. (This scheme was fully reported in LINK 93 —

July/August 1984).

Southampton association has 120 members and is run entirely on a voluntary basis.

The association has two holiday homes, organises outings and social events, and provides equipment and aids for members in the same way as many other groups.

Its other major success apart from the Bevois Mews scheme was the raising of £20,000 a few years ago towards the cost of building a workshop called the Hexagon Centre in Chandlers Ford, Hants, run by Hampshire Council (LINK 76, Sept/Oct. 1981).

Continued
Over
Page

Midlands

AFTER FIVE years of planning, thinking and fund-raising, Midlands Association opened its own sheltered workshop, Court Industries in April 1982 — the first local association to embark on such a venture.

Midlands Chairman, Mrs Dorothy Artingstall, writes:

"We employed a manager and a care assistant, and four spina bifida young people to start with. They were taught engraving and gradually we collected orders for signs, name plates and other similar work. They were also instructed in woodwork and we took over the making of the SHASBAH Trolley from Southampton.

We are still making these for the DHSs and for private or special orders. We now also make other articles in wood such as magazine

racks and cup racks, but will, in fact, tackle any small article at request. In addition to these we also make soft toys."

The workshop now has 12 employees with spina bifida and/or hydrocephalus.

The association has just finished refurbishing two new rooms at the workshop which it hopes to open as a secretarial training section, and a service to the public for typing, photocopying and printing.

Mrs Artingstall adds: "It is all very exciting seeing it develop but such a tremendous responsibility to raise £36,000 a year to keep the workshop viable."

Midlands has two very active groups of parents — in Coventry and Rugby — who very largely organise their own activities and parents meetings, but who come under the main local association's umbrella.

Somerset

IN ORDER to maximise its efforts Somerset believes in working with other groups. It stresses the importance of not duplicating services at unnecessary expense.

Total membership covers about 20 families, but the association is aware that there are about 50 families in the county with a spina bifida child to all of whom it has a commitment if the need arises. It doesn't run clubs or day centres itself, but has offered financial support to a workshop for the disabled being built at Wellington Youth Centre. It is a member of Taunton Deane Association for the Disabled.

In 1982 Somerset association built a specially adapted caravan at Loe in Cornwall. It handed it over to the John Grooms Association with the condition that Somerset members had priority in booking.

Somerset is totally dependent on voluntary help which seems to come from about six people. The number of activities is relatively few — about four social events each year. The declared intention of the association is to give financial and friendly support where needed.

Somerset has found that to have a project on the go attracts support from the public — a project such as the caravan in Cornwall. At the present the aim is to purchase battery cars for needy members.

Preston & District

SEVERAL members of Preston & District — 14, out of a total membership of 43 — do not have children with spina bifida. They have become involved for various reasons, some had children who died at an early age. The majority of members are aged 10-20 plus.

The association organises outings and sometimes long weekend trips. For the past two years there has been a long weekend in London which, because of its popularity, looks like being a regular event. Membership is spread over a wide area and so running a club or regular activity for the children isn't practicable.

A holiday home in Flookborough, near Grange-over-Sands is to be sold, and Preston hopes to buy another property in a more accessible area — probably on the North Wales coast where there is more activity suitable for teenage members. Like other associations, a good deal of time is spent on fund raising events of various kinds.

Wessex

THIS is a small but widely scattered association. There are 28 families with handicapped youngsters and young adults and 16 other members.

Two adults attend day centres and two others work — one for a taxi company and the other, association secretary Terry Poole, is employed by a local vacuum cleaner company.

Special Reports

Recently the association purchased a mini clubman when the lease for motability ran out. It is used by the association's own voluntary welfare officer, and to help the older members to learn to drive.

On the social side, skittles evenings are popular, and there is a Tuesday Club during the holidays which gives members a chance to meet and the children to play together.

Chesterfield & District

THIS association is trying to form a junior committee to encourage the teenagers to take an active part. The majority of the youngsters are now in their teens. Chesterfield has its own holiday chalet at Bridlington.

Gainsborough & District

EARLY in 1984 this association was brought to life again having been dormant for some time. A completely new committee was formed and now membership is 40. The ages of the spina bifida members range from 18 months to 23 years.

There is a members' meeting each month with a different activity. It covers recreation and learning. There are also regular monthly social visits to each family, and a 'parents corner' to enable parents to talk amongst themselves about problems and needs.

The association hopes to build up funds in order to provide grants for holidays, hospital visiting, and death grants and tokens to help with Christmas expenses. It is striving, too, to build up a stock of aids and equipment for loan to members in emergencies.

Gainsborough is very pleased that since the formation of the new committee, links with local hospitals have been strengthened and in this way it hopes to make contact and help many more families.

Secretary, Mary Hawkes, writes: "Liaisons are also to be made with all associations and organisations who could be of help at some time in the future. We feel that a close relationship is very necessary with every group which deals with the handicapped in any way. As the Secretary I feel that only by helping others (in whatever way) can one expect to be helped."

Local Associations

Hull & District

AN ANNUAL eight day trip to Holland for the young members is organised. For the past five years the group has stayed at Valkesburg, a town which gives easy access to both Germany and Belgium. This is seen as an educational trip — a holiday that will help to widen the horizons of the young members.

The association has about 80 member families. Ages range from 2-44 years. The association chairman is Philip Brown who has spina bifida and is the son of Mrs Gerritje Brown, founder member and honorary secretary of the association.

Hull has a holiday caravan at Shipsea, and provides practical help for members in the form of equipment (lightweight chairs, trikes, sewing machines, typewriters, etc.), grants towards home adaptations and grants for hospital visiting, etc. The associations also managed to arrange a Christmas party and a trip to the pantomime each year.

North East London (NELASBAH)

THE ASSOCIATION is particularly pleased with the results of its Holiday Home Appeal which has enabled it to purchase a specially adapted brick built bungalow for holidays at Greatstone in Kent. NELASBAH members have first opportunity to use it and then it is made available to other handicapped

Worcestershire

THE VENTURE Centre in the centre of Stourport on Severn has become the nucleus of activity for Worcestershire local association. It has rented the centre, formerly a library, for the last five years but earlier this year it purchased it from the County Authority of Hereford.

It is situated in a busy road adjacent to the town War Memorial and this means that grass surrounds and flower beds are all well maintained. Having purchased the centre, the association's first priority is modernisation of toilets and kitchen.

The centre is used on a regular weekend basis for all sorts of activities attended by disabled members and, sometimes, parents. Light meals are provided at lunchtime as members spend from 11 am until mid afternoon there.

The association has two vehicles which transport members to and from the Venture. There is a rota of drivers and escorts.

On the first Saturday in each month a fund raising sale is held at the centre.

Worcestershire charges a family annual subscription of £2. There are about 53 disabled members who receive cash gifts on their birthdays and at Christmas. Outings are arranged, and these together with fund raising activities keep the association very busy.

"As we are seen to be trying to help ourselves, we receive good financial support from the area around us" writes Jack Norman, Vice-President of the association. Recently, for example, 12 Supa Scooters were presented to members of the association funded mostly by individuals and organisations.

groups. The association is hoping to run training weekends at the bungalow for its youngsters to help them to become more independent.

There are 100 members, 28 of whom are handicapped. A recent fund-raising effort has financed the purchase of much needed equipment for members. The General Fund caters for the needs of members including welfare, socials, outings, and parties. A newsletter 'Contact' is distributed to members each month.

meet monthly, either to hear a special speaker or for a more social get-together. There are already PHAB clubs, Free Wheelers and other activities in the area and members are encouraged to participate in these. There is a good swimming club and access to two swimming baths. The association occasionally has its own swimming parties.

There are outings and social activities and of course a good deal of fund-raising as Staffordshire tries

Staffordshire

STAFFORDSHIRE manages to

Continued over page



Members of two local associations — Warrington and Liverpool — have got together to form the only Baton Troupe of its kind in the country — maybe in the world — with all the members in wheelchairs.

Those who attended ASBAH's Spring Conference in 1983 will remember seeing them perform.

The group — the Michelle Aires Troupe competed last year in the Isle of Man World Championships where they received tremendous applause.

The members are Julie Shaw (leader), Janet Barker — both of Warrington association, and Marcel Caddick and Jane Shepherd of Liverpool association.

They practice at Speke Community Centre every Sunday morning, and are urgently looking for more girls to join them — girls of any age who would like to give baton twirling a try.

Continued from page 15

to give £1,000 a year to national ASBAH. This is over and above its commitment to help parents with travelling expenses involved in hospital visits, and to provide aids and appliances where necessary. It also gives other general support to its members . . .

“providing all manner of information concerned with such things as applying for allowances, getting a person insured for a holiday abroad, pursuing the DHSS, or the local council, and with making sure the general public knows of our existence.”

Cambridge

THERE are 11 handicapped members aged 7-23. Being one of the smaller groups it has found that its holiday chalet at Kissingland is under utilised and is planning to sell it. Generally social activities do not attract very much support although coach outings to various places seem to be the most popular.

Bromley and District

THE MAIN commitment is in providing a field worker who is employed for two days each week, the maximum the association can afford at present. “He is our biggest asset and provides a super service.”

There are about 65 handicapped members, mostly aged 9-27 years although the age span does run from 1-56 years. One of the members who is slightly disabled runs a club for 16+ disabled and able-bodied. This is well organised and enjoyed by a great many people of mixed disabilities.

The association has a mini bus which is well used. Regular outings to places of interest are arranged, and the association takes part in local fetes to raise money. It has a Christmas party for members each year.

Two of the members serve on Bromley and Lewisham Association for the Handicapped.

Warrington & District

THERE are 36 member families representing 37 people with spina bifida and hydrocephalus (aged 2-30 years) and eight members who are not parents or disabled. The main commitment centres on their holiday accommodation in Wales.

Sussex

SUSSEX is a large and active association with a paid part-time secretary and two field workers. It has been very successful in arranging activity weekends for its young members; it has recently been successful in getting a Post 16 clinic started, and this year should see the completion of a housing project.

With the bulk of its members aged 12-20, Sussex association has made special efforts to meet the needs of this age group. It runs at least three mini breaks each year for different age groups. This year an early Spring weekend was held for 15-17 year olds, a weekend in June was for those aged 12-15, and this Autumn a weekend is being held for the 18 plus group to discuss housing.

A project which has taken patient planning since 1978 is a Post-16 Clinic which started up earlier this year (see LINK, May/June 1984). Sussex had been concerned at the complete lack of medical care and supervision for its young adults once they had left the ‘shelter’ of the children’s hospitals. The association is contributing £2,000 a year in order to get it off the ground, and the remaining £5,000 is coming from the District Health Authorities and Chailey Endowment Fund.

At the end of this year a housing project which has taken six years to plan should be completed. This is the conversion of a 1930’s house in Worthing, in conjunction with the Downland Housing Association, to provide nine units plus a warden’s flat. This will be a ‘half way house’ where young people can learn to live as independently as possible before moving on.

Sussex association holds special meetings as and when needed. Last year there was a day for new parents, a day for young people over 16, and a special meeting on incontinence aids.

There are three local groups, Brighton, Crawley and Hastings, who organise their own social get-togethers, parties, etc., for members.

This is more practical than having regular monthly gatherings for all association members in the country, because of the large geographical area involved.

There are over 300 families known to the association in the country and

Special Reports



A moment during the mini conference for over 18s organised by Sussex Association in the Spring of 1983.

it has a membership of over 400. At the last ‘census’ in 1982, it had 32 disabled members born before 1950; the biggest numbers were born between 1964 and 1972; but there has been an increase in the number of babies since 1979. In February 1982 there were two babies under 3, and the pattern has continued.

The association contributes 75% of the cost of two field workers, one for East Sussex and the other for West Sussex. National ASBAH provides the remainder of the cost of this important service. Margaret White has been the part time paid secretary for 8½ years.

A mobile home at Selsey was given to the association by the Magpie TV programme 10 years ago. A monthly newsletter is sent out to all members, and a special newsletter is also produced for young disabled members aged 13 plus. This includes news and items by the young people themselves, plus photographs, etc. In theory it is quarterly.

With the need to raise over £30,000 each year, fund-raising of necessity takes up a good deal of the time and energies of this flourishing local association.

Local Associations

Bucks & E Berks

THIS association began life in a smaller form in 1966. Today with over 100 members most of the people it is concerned with are aged up to 21. The association is run by its members in a voluntary capacity, but it does employ a part-time field worker whose help and advice is invaluable to parents.

The need for holidays features prominently in the association's thinking. It owns a chalet near Great Yarmouth and a Holiday Fund exists to pay for holidays — such as an overseas holiday for a child with his school, or Red Cross holidays, to give mothers a break. Other activities include day trips, parties and meetings with special speakers. At present the association is helping youngsters to have driving assessment at Banstead Place and to participate in LIFT activities by providing transport.

Grantham & District

THIS SMALL association not only has a holiday chalet — at Chapel St. Leonards on the east coast of Lincolnshire — but has also purchased a four berth touring caravan which it hires to members of the association. When not in holiday use the caravan is handy for fetes, galas and other fund-raising events. The chalet is well used by friends and relatives of members, and the touring van enables families to choose whether they go 50 miles or 500 miles.

Grantham has 16 families in the group, and four of these have no handicapped person within the 'immediate family'. It has a permanent 'Aids for Independence' project which aims to promote independence in its handicapped members. This helps to pay for driving lessons, car adaptation, etc. or the provision of some access amenities for members with a home of their own.

Various outings and social functions are organised and some of the members attend a PHAB club and a junior PHAB club is being arranged.

Kent

KENT, WITH 89 families, has a paid secretary and a committee of seven. One member who has recently

Leicester

LEICESTER association was formed over 15 years ago, in which time it has gone from strength to strength and is now well established and respected.

The association reports: "The past fifteen years had seen many changes — in the early days we bought trolleys and buggies and other equipment — most of these can now be obtained through the health service. We also started a Hospital Visiting Scheme which is still running, whereby a member can benefit from a weekly sum — currently £8 per week. Also in 1972 the Red Cross Toy Library was launched. And I hope that we will carry on giving this Toy Library our support since it has proved that there is a very real need."

Much more interest is now being shown in sport for the disabled and a club is to be established locally. The association has its own Thursday evening swimming club which is well attended.

It has always had an interest in providing holidays for members and several years ago it opened a holiday chalet at Winterton on Sea, thanks to the generosity of the Variety Club

joined the committee has spina bifida herself and is a mother of two boys.

"She has brought an added dimension to the monthly meetings" writes the Secretary.

The association has the services of a fieldworker who was originally funded by the Manpower Services Commission. When this grant ends this year she will become part of the normal national field work scheme.

Like many other groups, Kent has its own holiday chalet — at Romney Sands. An annual outing is organised each summer, and members are kept in touch, mainly through a bi-monthly newsletter.

Among the 89 member families there are 71 who are disabled — the majority of whom are in the 10-18 age group.

Greenwich

GREENWICH is one of the associations that has put a major effort into establishing its holiday bungalow. With very little money readily available, Greenwich buckled to and paid off the original purchase price of the bungalow situated at Westgate on Sea, in double quick

of Great Britain. Another holiday home — this time in Wales — has recently been opened.

Generous local support enables the Association to respond to many requests for help during the year — not only financial help, but also for information gained over the years.

Equipment and aids are available on long term loan. Financial help is given towards the cost of modifications to cars, and to help members wishing to take part in the Motability car leasing scheme.

The association maintains a library and produces a very informative Year Book. These publications and LINK are all available free to its members.

Last, but by no means least, Leicester association, in conjunction with National ASBAH, employs its own field worker whose practical help and advice has proved invaluable not only to families with spina bifida and or hydrocephalic members but also to the local statutory authorities.

Leicester makes a point of being represented locally and nationally so it can have, at its fingertips, up-to-date information to help its members with any problems.

time. In 1982 further alterations were carried out. It has three double bedrooms and can sleep nine.

Each year priority is given to its own members in terms of early booking, but about a third of those using the bungalow are from other associations in all parts of the country. For several years a group of underprivileged mentally handicapped children, with their teachers, from a school in Woolwich have had a free week at the bungalow.

Greenwich acknowledges that it has had help from many places and mentions in particular Gardens for the Disabled. The fruit trees they gave are now beginning to provide fruit for visitors.

Shropshire

THIS association has 68 spina bifida members aged 1-23 years. It certainly doesn't lack for originality. It has its own brass band 'New Ventures' which is becoming well-known at concerts in the area. There are 12 children in the band, and funds raised by the association pay for instruments and tuition.

Continued over page

Continued from page 17

Shropshire has two caravans — one at Barnstaple in Devon and the other at Prestatyn in North Wales. It is hoped that in time the older members may be able to enjoy a holiday on their own at one of the caravans without parental supervision.

One of the many disappointments however is the lack of interest shown by members. A number of interesting and useful meetings have been organised with guest speakers specially invited. More often than not only committee members have turned up.

Trafford & Salford

THE LATEST activity of this association goes under the name of 'Stepping Stones'. It is a scheme designed to help those over the age of 18 learn to live independently.

The idea is that a group of young people should be able to live together for a short period (say 2-3 years) in a sheltered but independent environment, helping each other and calling, where necessary, on community support systems. The association envisages that the unit would house four to five young people and consist of bed-sitting flats and community facilities.

After acquiring confidence through independence each young person would be expected to return to his or her own district, allowing others to take their place.

The association is getting the support of the Methodist Housing Association and is in the process of looking for a suitable site.

Trafford and Salford has 132 members, 87 of whom have spina bifida and/or hydrocephalus. Most members are aged 11-30.

Apart from providing an information service, and grants as necessary, the association encourages members to get together at social events. A Family Day, once a year, has proved so successful that it is considering holding this twice a year. There is a fortnightly Friday Club for those aged 13-25.

The association has a small, but busy office, in the centre of Urmston and Mrs Jean Robinson is the paid secretary, working four mornings a week to keep the association running smoothly.

Bolton & Bury

THIS IS an energetic group in a

literal sense. A number of youngsters are involved in wheelchair dancing to a very high standard.

They are encouraged by Richard and Kathleen Reading, former UK champions who are association members.

On alternate Sundays a small group of swimmers visits a local pool and the association's sports team, which is affiliated to the British Sports Association for the Disabled (BSAD), is a regular competitor in all manner of events. Other youngsters are actively involved with Riding for the Disabled.

There are 61 members, 22 of whom have spina bifida and or hydrocephalus.

Whitchurch

ALTHOUGH very small — only 7 disabled members — this association has had enough get-up-and-go to organise a holiday in Majorca at Easter this year for all the members and their parents. It proved a very enjoyable holiday, although members were disappointed at the facilities and help given at the Majorca end.

Whitchurch also manages to supply and maintain Batric cars, three wheeler bikes and other equipment.

Belfast

THIS IS a rapidly growing branch of

Special Reports

the Northern Ireland Association with membership over the 180 mark and three or four referrals each month. Ages of members range from the new-born up to 70 years, but most are under 25.

Belfast has holiday accommodation in 3 locations — specially adapted chalets at Ballywalter and Ballyferris, and a caravan at Ballycastle. All are available to members at a nominal charge. The association arranges various outings and activities for members such as barbecues, discos, summer outings, and shopping expeditions.

Antrim

THIS is a fairly new branch started in February 1982. It has 25 members including parents and friends. There are 11 children with spina bifida, their ages ranging from 2-16 years. Members meet once a month in Antrim Day centre and there is a good attendance.

Antrim reports very good support from the public for its fund-raising efforts, and since it started it has been able to buy a Batric car for a boy of 16, and give £500 to National ASBAH for research, A £50 clothing allowance is given to each youngster twice a year, and there is also enough money for summer outings,



Members of Cannock and Walsall local association turn out to raise money by means of a sponsored wheelchair push. Fund raising takes up a good deal of time for all the local associations.

Local Associations

a Christmas party, and Christmas and birthday gifts.

Coleraine, Ballymoney and District

THIS IS a relatively young group with nine spina bifida children and only two young adults, a boy of 16 and a girl of 21. It was formed in 1979.

It has an eight berth caravan in Ballycastle on the Co. Antrim coast, and members meet every 2 months.

"Although we are a small group our members are always very willing to help with our fund-raising events, such as flag days, fashion shows and cake sales. The general public in this area is becoming more aware of our association and so we do benefit from donations. This in turn benefits our children enabling us to provide equipment, give them an annual clothing grant, a holiday grant, and a gift at Christmas. If the need arises death grants are provided."

Mid-Wales

THERE are only 15 members living in all parts of Mid Wales from Craven Arms in Shropshire to the Welsh coast some 78 miles away. Members sometimes do round trips of over 100 miles to meetings and this means that they get together only about twice a year. They usually keep in close contact by phone.

Remember the Round-up pages of LINK exist to carry news of Local Associations. Keep LINK informed about what is happening

Bristol

BRISTOL local association celebrates its 18th birthday this year along with national ASBAH. They have been 18 busy years and the association has two major projects 'under its belt'—the building of a special Spina Bifida Unit at Frenchay Hospital, Bristol, and the setting up of a craft workshop for members.

The association put all its efforts into the Unit at Frenchay because of the need for one centre where spina bifida children could go for all their care instead of having to trek all over Bristol area to see various professionals.

It opened in 1970, and an extension was added in 1976. The total cost of this was £24,500 and Bristol association also bought special equipment, and paid for the first playgroup leader. All the costs have now been taken over by Frenchay hospital, and the unit is also used by children with other handicaps. It has proved an enormous boon having the one centre.

Last year, the association opened a Craft Workshop in Bristol where up to six trainees—young members of the association—work for four days a week. A supervisor is employed by the association and she provides transport to and from the workshop using the association's own mini bus.

In June 1983 Bristol association earmarked £25,000 to finance the workshop up to June 1985. The workshop produces cotton rugs and woollen garments for sale, and hopes, in time, to become a profitable concern.

Bristol association has a membership of 180 families—not all of them having someone in the family with spina bifida or hydrocephalus. Many of the original

members are still active, although there have been plenty of changes on the Committee. The Committee is split into various sub committees, and a new fund raising committee is formed every time a large fund raising event is planned.

Money is raised by events such as fetes, draws, jumble sales, dances, coffee mornings as well as by larger fund-raising events such as house-to-house collections, bucket in pub campaigns, mini car raffles, sponsored walks, etc. In the first ten years donations amounted to over £40,000.

Like many other associations Bristol is aware of the needs of the teenage members, and their futures. The craft workshop is a first attempt to provide employment.

The association is also continuing to help younger families, and to provide welfare assistance, social contact, help with holidays, etc. and financial assistance for hospital visiting. Each request for help is considered on its own individual merit.

Much financial help has been given by Bristol association to various projects such as extensions to buildings at Bath school for Spastics, alterations at Frenchay Hospital, financial grants to John Grooms Housing Association. The association has helped to buy special beds in local hospitals, surgical instruments for specialist operations by local surgeons. It has supported clubs for the disabled, and given assistance for school holidays, swimming, horse riding, wheelchair dancing, and vocational training and has provided equipment for members as necessary, such as lightweight wheelchairs.

Bristol association has been affiliated to National ASBAH from the start and expresses its gratitude to the national organisation for its help over the years.



The Spina Bifida Unit at Frenchay Hospital.



"Cohesive"

OSTOMY SEALS

The most modern ostomy seals available have been formulated to do away with some of the irksome tasks of the past. Cutting to fit with scissors for instance is now a thing of the past, you simply stretch the "Cohesive" to the desired shape and mould it to fit the stoma. This is possible because "Cohesive" Ostomy Seals do not rely upon a plastic film covering nor laminate to stabilize the substance.

roll it mould it ..

stretch it to fit !

"Cohesive" Ostomy Seals can remain in position for several days without renewal, due to a slower rate of dispersion than most other products. Folds and scar tissue surrounding the stoma can be filled with "Cohesive" which forms a perfect base for most ostomy appliances. Additional adhesives are unnecessary, "Cohesive" Ostomy Seals are extremely tacky upon both surfaces. "Cohesive" Ostomy Seals can be used on broken or excoriated areas of skin, to produce a soothing effect which allows healing to take place. "Cohesive" due to its slow rate of dispersion, is excellent for urinary diversions and for fistulae.

Available large size 95mm (3 3/4") dia., small size 50mm (2") dia.

"Cohesive" Ostomy Seals are so easy to use.



SALT & SON LIMITED
 220, CORPORATION STREET
 BIRMINGHAM B4 6QR ENGLAND
 Telephone: 021-233 1038

If you would like to try "Cohesive" Ostomy Seals please complete the coupon and return to Salt & Son Ltd. & you will receive a sample & full instructions free from charge. Use the Freepost address, a postage stamp is not necessary.

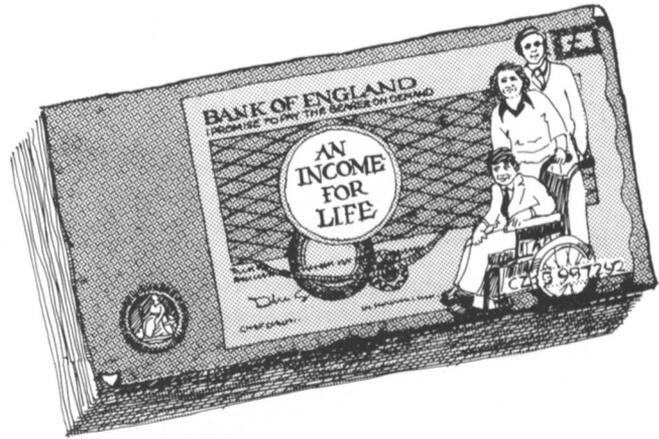


Name & Title
 Address

Please tick in appropriate box LARGE SMALL
SALT & SON LTD · FREEPOST · BIRMINGHAM B4 6BR

THE SECOND of a series of articles by John Taylor covering the financial needs of your children when various events occur.

Don't underestimate the true value of a wife and mother



THE FAMILY "money machine" was the subject of the first article in this series. The object of this article is to show that a family has another asset which enables the "money machine" to function efficiently.

I wonder how many of you envied that affluent family featured in the TV programme "Upstairs — Downstairs". They have a full staff to "do for them" and seem to do little else themselves other than solve problems, enjoy life and entertain royalty.

Do you wish sometimes that you had a staff of servants to look after the needs and comfort of your family? What stops you from having one — assuming, of course, you do not have one at present. I would venture to suggest it may be that the cost would be a little inconvenient!

Have you ever looked at the cost of running household staff? (No I am not advertising a domestic agency.) For the purpose of arriving at the cost of our staff, the following assumptions have been made:—

- The pay is based on current wages set by Employment Agencies' average fees for different jobs undertaken.
- Thursday is used in the example as that may well be the "hectic" day of the week.
- Some of our staff will have Sunday as a day off.
- We expect service from 7.15 a.m. until 8.00 p.m. weekdays and slightly less hours on the weekend.
- Our family has children.

THURSDAY

Time	Job	£
7.15 — 8.15 a.m.	Cook/waitress/dish washer	2.10
8.15 — 9.00 a.m.	Driver	1.41
9.00 — 10.30 a.m.	Clothes washer	3.30
10.30 — 12.00 noon	Shopper	3.35
12.00 — 1.00 p.m.	Cleaner	2.21
1.30 — 3.00 p.m.	Cleaner	3.31
3.00 — 4.00 p.m.	Cleaner/washing dryer/driver	1.10
4.00 — 5.00 p.m.	Childminder	1.97
5.00 — 6.00 p.m.	Childminder	1.97
—	Cook	2.24
6.00 — 7.00 p.m.	Childminder	1.97
—	Waitress	1.84
7.00 — 8.00 p.m.	Childminder	1.97
—	Dishwasher	2.21
	Total	32.36

Based on the table, the annual cost of full staff would be £9,550. This could account for few of us having "domestics" — but is that so true? I know that I do not get involved in much cooking or cleaning or looking after my children, although it certainly gets done! I tend

to leave all those jobs to my housekeeper, who is unpaid and my wife.

Perhaps you know of others in a similar position? I would suggest that the majority of families have a full household staff embodied in their wife/mother. Very few wives, however, are paid the sort of wage they would command on the "open market" (even mine).

Some other duties omitted from the list are ironing, gardening, decorating and, in particular, nursing when members of the family fall ill, as well as catering for the special needs of handicapped children. Just as husbands are a "money machine", so a wife is a valuable asset to her family. Just as the family should be financially protected from the loss of their "money machine", so they should be protected against the loss of their "staff".

Realizing that the cost of replacing most of the duties of a wife would be £9,550, not allowing for any cash earnings, then, as with her husband, she should be insured for an amount that could generate at least £9,550. This would be around £120,000.

Many readers will now be thinking a variety of thoughts — "that amount would cost too much" or "my mother-in-law could help out (or my mother, sister, etc.)".

Firstly, the cost of the cover required is not so out of reach and, should it not be convenient to do the complete job, then going part of the way is not such a bad idea. The cost of insuring her for £120,000 would be similar to that for insuring a man for £100,000 (first article) i.e. about £18 per month. In order to keep the cost down, it is possible to cover both husband and wife on one policy (which would not cost double the amount for one).

Secondly, it is one thing to look after grandchildren for a weekend or even a week but to do so for the years ahead which were earmarked for a peaceful life and a rest after the demands of working for forty years and bringing up their own family is quite another thing.

So, in the interests of the father of the family and his children, bearing in mind the special attention required by our disabled children, it must be a good idea to do something (now) about ensuring the continuation of the home duties provided by our wives.

Should you require any assistance in the above area, or have any comments, I would be delighted to hear from you via ASBAH.

LIFT stages a 'College Roadshow' to meet students

OVER THE past few months, small teams of ASBAH's National Office staff have been visiting many of the Special Further Education Colleges in order to encourage spina bifida students to take more interest in ASBAH and to become more aware of the services we can offer.

Under the LIFT banner we deliberately adopted a very informal approach and at several colleges held a disco to round off the proceedings.

Two different approaches were tried:

- talking to all the students in a large group with each member of the team saying a few words about particular services;
- dividing the students into three or four groups and rotating the groups around the ASBAH Staff, who had about 20 minutes informal discussion with each group.

We found that in most cases, the latter approach worked better and provoked a more thoughtful response from the students.

In both cases information about the work done by other ASBAH staff not present was given, and it was stressed that the contacts we were giving the students would be of particular value to them when they eventually left the supportive environment of the college.

At most colleges, we were talking to a mixed disability group and so lists of other organisations were provided so that the non-spina bifida students could contact our

counterparts in their own disability group. We also distributed a variety of ASBAH information sheets and sold a number of the new 'Making Our Way' booklets and the reprinted 'Sex For Young People With Spina Bifida Or Cerebral Palsy' publication.

A great deal of interest was shown by the students in a slide show given by the Disabled Living Advisers about spina bifida and hydrocephalus and their implications. Some spina bifida students found it impossible to accept that the explanations given actually related to themselves as they had believed something different for as long as they could remember and reacted to our talk by saying they had 'spinal injuries' rather than spina bifida. However, many other students were glad to have the opportunity to have a frank discussion about their disability.

We had very positive feedback from all the colleges and most have expressed interest in having another visit from us when they have a fresh intake of students. However, the real success of our visits cannot really be assessed until the present students have left and we will be able to see whether there is greater awareness of ASBAH's existence and a corresponding increase in the number of enquiries we receive.

VIVIEN HARPER
Lift Organiser



Get out and about with the
SPEEDWELL SUPAKART

Get out and about with the Speedwell Supakart.

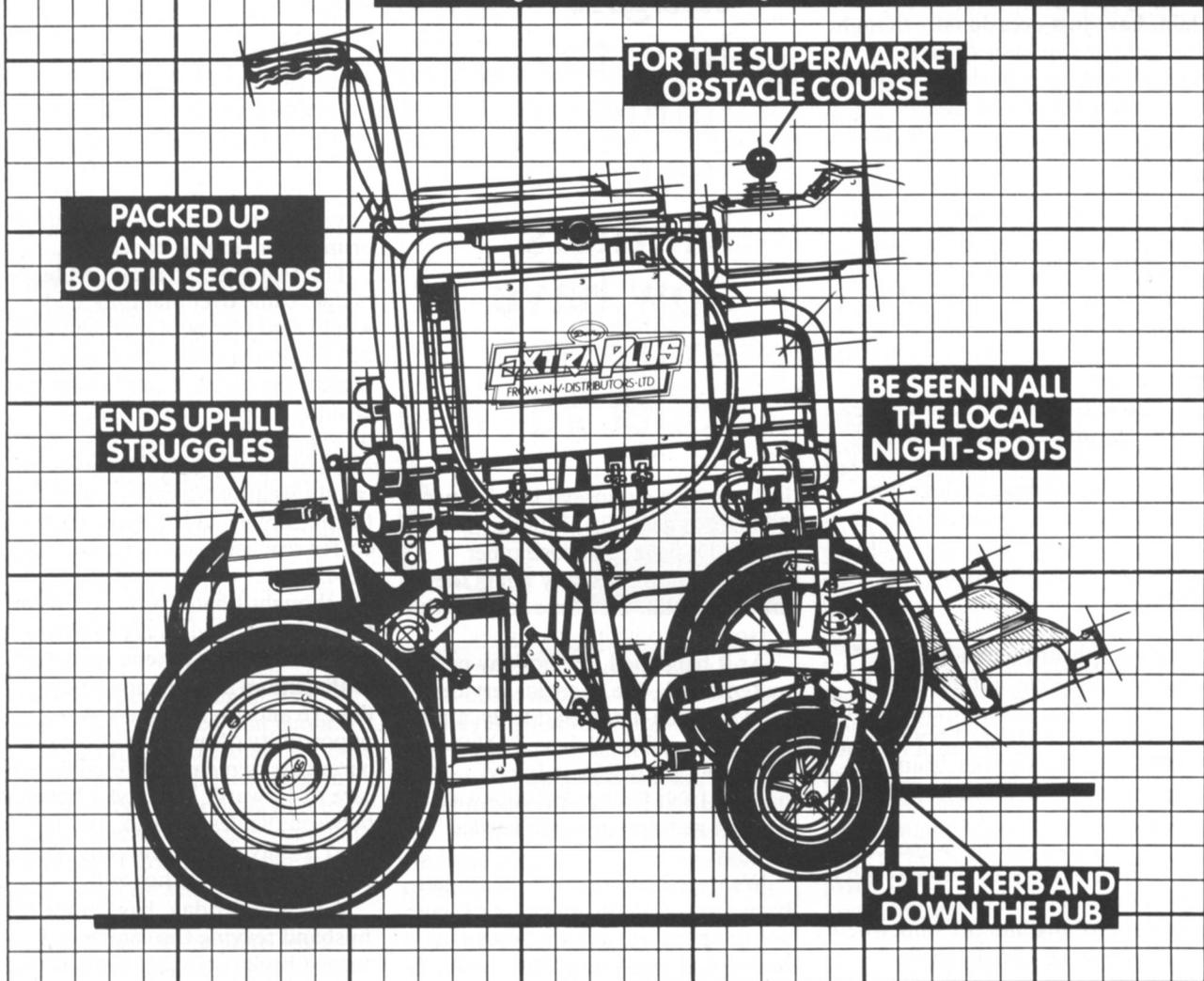
Designed primarily for physically handicapped but is suitable for all children from 6 to 16 years of age who have reasonable strength in their hands and arms.

The Supakart is a rugged, stable, outdoor vehicle which has a range of six miles, will mount shallow kerbs and climb steep gradients.

To have one, is to have fun, and you will see more places and people.

For further details contact:
SPEEDWELL ENTERPRISES,
NORTHAMPTON AVENUE,
SLOUGH, BERKS.
Telephone: SLOUGH 72249

Look what happens when we draw on your experience.



A lot of people have very positive ideas about their ideal chair. Listening to them has helped us perfect the Extra Plus – a chair for those who spend a good deal of their time out of doors.

The Extra Plus responds to your every need, whether you're gliding up a 1 in 4 hill or getting a cup of tea indoors. This is because it combines power with manoeuvrability. As well as simple fingertip control and a host of features that make it excellent value for money. A heavy duty frame and orthopaedic seating ensure it's tough on the street but not on you.

Another reassuring plus is that it's got all the proven Dudley technology you

expect from NVD, the leaders in mobility products. So if you'd like to know more please contact us. After all, the Extra Plus is the chair you helped us design.



Cut out this coupon for your free brochure and send to:
N.V. Distributors Limited, Soothouse Spring, Valley Road
Industrial Estate, St. Albans, Herts. AL3 6BR.

TELEPHONE: ACTION LINE 0727-34255

AL

NAME	
ADDRESS	

WHO NEEDS WHOM THE MOST?

HOW MANY mothers, like me, having gone through the various stages, over the last 18 years, of worrying, nursing, caring, encouraging, cosseting and even gently bullying their handicapped child, have just occasionally thought how great it would be to have a family break, or a husband-and-wife weekend, without said child?

If someone we could really trust would accept the responsibility for just a little while, we could spend a little time doing the things we want to do, and visiting the places we want to visit without considering if they are suitable for a wheelchair. The more impossible it seems, the more we fantasise. BUT — given the opportunity — could we do it?

As Edward has got older and less dependent on us, we have thought how nice just to have a short break. Don't get me wrong, we love him dearly, and have no regrets that he is ours, but we feel this break would help us continue with renewed vigour.

Two years ago, the Social Services promised Edward a two-week holiday in the long summer break. As father is a teacher, we thought it would give us the best of both worlds — time to do our 'thing', then time to be with Eddie doing his 'thing'.

From the moment the wheels were put in motion I was overcome with a sense of deep guilt. How could I consider pushing him off somewhere — anywhere, so I could enjoy *myself*? What if he became ill? Would he settle? Would he understand why we had done it? Husband and other two sons thought I was mad. We never have trouble with him settling in anywhere. When he goes into hospital he is away to survey the surroundings as soon as he is on the ward.

Visiting time goes like this:

"Hi Mum, what are you doing here?"

"Well, I thought I'd pop in and see how you are."

"I'm fine thanks, are you going now? I'm missing this programme on telly."

But still I worried, and everyone else got cross with me. But then, even though they are all involved, it

After years of being taught how to hang on perhaps Mothers now have to learn to let go

isn't such an emotional involvement, 24 hours a day. Their minds, naturally, have to absorb other issues because for many hours they are away from the home coping with personnel, decision making, etc.

As it happened, the holiday never materialised, due to social services muddling the dates. Suddenly, I no longer felt guilty. Relieved? Not likely, once it wasn't going to happen I felt furious because we weren't getting our much needed holiday.

We have had breaks. Edward has been away with the school, or I have got out because father has been at home, and vice-versa. But, if what I am doing is not normal routine, why can't I relax and enjoy it?

By the time I return home, in my mind I've gone through — a blocked shunt (hasn't done that for years), fall from the wheelchair, (hasn't done that either for years), fall from his stair lift (he's never done that), only to find him playing happily, usually unaware of either my departure or return, and I firmly vow never to be so silly again, until the next time!

I assure you, the wheelchair isn't fastened to the ends of my arms with superglue, but if I am in a situation where he would normally be with me — and he isn't — I keep wondering what I've forgotten. For instance, sightseeing alone in London on the day of ASBAH's 18th Anniversary

party (Eddie was a guest and I had five hours to spare), I thoroughly enjoyed browsing down Portobello Road — impossible on a crowded Saturday with a wheelchair, and I covered a lot of ground by tube — again, impossible with a wheelchair, but I still had the feeling I had forgotten something.

Feeling peckish, I dived into the nearest Wimpey for a burger and coffee. Then, standing there with my tray, I couldn't find a seat (and how I needed a sit down), I stood at the brunch bar sipping my coffee.

The Manager, so it said on his badge, came over and told me I would find plenty of seats upstairs, but I automatically told him I couldn't go up there and stood my ground. Then it dawned on me — no wheelchair. I grabbed my tray and started upwards. Half way up, I caught sight of his face — and I'm firmly convinced he thinks their coffee reaches parts other coffees do not reach!

I thought I had learnt my lesson five years ago, when my husband was to attend a weekend conference in Blackpool and the other boys, then 16 and 14, seeing a great opportunity of having a super parentless two days, offered to take care of Edward. For days I hovered between the desire to go, and the need to stay, but, eventually, agreed to let them have a shot at it.

4.15 p.m. Friday, bags in the car, husband revving the engine — I turned back (isn't that supposed to be bad luck?) at least six times with fresh instructions. Not taking their eyes off the TV once, all the boys kept saying was 'Bye, Mum'. Finally, on the way, I worried — did I tell them about his medicine? Would they remember to change him? Would they make sure he had a wash? I knew they wouldn't.

Booked in at the hotel, fed and watered and on our way to the Welcoming Dance, I just made a quick 'phone call:

"What's up Mum, something gone wrong?"

"No, no", I stammered, "Just making sure you're OK."

"Oh, Mum, give over."

I hung up hurriedly.

On Saturday, I actually lasted until noon before seeking a call box,

and felt a little disconcerted when no-one answered. Groomed and perfumed that evening for the second dance, I made one more call. All was well, they had been bowling earlier: "must go, we've got mates waiting".

Sunday afternoon, on the way home, I felt myself relaxing. As we pulled into the drive, we could see our neighbour under the bonnet of his car, with Edward the other side offering his opinion.

"Hi Mum", he called.

"Hi there", I replied, "are you OK?"

"Yes thanks."

"Have you missed me?", I blurted out.

"Why, where have you been?, came the reply.

I am going to Blackpool for the same event this year, and my husband has put his foot down firmly. Edward is staying with Philip, and I hear myself already saying "I hope you give him proper meals and remember he has to be changed often, so don't leave him alone too long."

"Don't worry Mum", he says, "When I go to the Pub, he'll go to the Pub." I wonder why I don't feel reassured?

Trying to be very honest with myself, I have decided that actually I need Edward far more than he needs me. He is my crutch. Having spent all these years encouraging him to be as independent as possible within his capabilities, I don't really like it, that he needs me less than I need him.

When I was able to go to work, I wasn't so intense about things, but now I am home all the time, I need to be needed. Because the other boys are able-bodied, strong, healthy, specimens, I accept quite easily that

"I stood at the brunch bar sipping coffee. . . . The manager said I would find plenty of seats upstairs, but I automatically told him I couldn't go up their. . . ."

"Then it dawned on me — no wheelchair. I grabbed my tray and started upwards. Half way up, I caught sight of his face — I'm firmly convinced he thinks their coffee reaches the parts other coffees do not reach."



at 19 and 21 they are growing away from home and us — the eldest has already been in the forces for four years. But it was never expected that Edward would live this long, so I never anticipated this stage in my life, or his either. In the early years, we lived every hour, day, week as it came, every one was a bonus. With the able-bodied you always have to be one jump ahead. Could that be why it is so difficult to let one go, but acceptable to let two go?

Perhaps it would make more sense if mothers could get together and talk all this through. Out in the

open, problems always seem nonsensical. After all, wasn't that how ASBAH came into being? The need for parents to meet and talk with other parents about spina bifida and hydrocephalus grew into meetings and into Associations. We coped because we knew that our handicapped children needed and would continue to need a lot more from us than our able-bodied siblings.

Eighteen years on, that has changed. There are self-help groups, Independence Training courses, Motability, financial allowances. They are encouraged on all sides to 'go it alone' — and so they should. But for those of us who were in at the beginning of ASBAH, it is a little hard to swallow all at once. It is only natural that our Associations are turning to helping the teenagers to cope with their lives in this fast moving, shrinking world. Yet couldn't it be that all this activity has over-shadowed the fact that parents, especially mothers, after years of being taught how to hang on, now have to be shown how to let go.

MRS JUNE DAVIES
Staffordshire

Please let us have your views: would it be a good idea for National and Local ASBAHs to arrange for mums to get together to discuss this?
Editor.

Front Cover

Stories of Independence and Achievement

Boys' Brigade. It is the highest award attainable and Jeff, who is blind and has hydrocephalus worked very hard for it despite having a grand mal fit in November.

His mother writes: 'He is blessed

with great determination and self-motivation.'

Part of the work involved service to the community, and for this Jeff spent about 40 hours working for the local hospital radio service.

He has been a pupil at St Vincent School for the Blind and Partially Sighted for 11 years and is hoping to pursue a business studies course at a local sighted college this Autumn.

Congratulations to Jeff and good luck for the future.

THE TOP two pictures on the Front Cover were taken at the independence week organised by Midlands ASBAH at Solihull earlier this year. They were taken by Claire Lyon, an occupational therapist on the course, and show a road safety talk by the police, and a make-up and personal care session for students and helpers.

THE BOTTOM picture shows Jeff Newall of Eastham, Wirral receiving his Queen's Award in the

Bugs Bunny Band in Berkeley Square

PEOPLE in Berkeley Square one day in June might well have vowed to "take more water in future" when a marching band of Bugs Bunnies appeared, to contribute to the air of festivity resulting from ASBAH's third year of running the Monopoly Marathon.

Madeleine Legg, was, once again, responsible for the daunting task of motivating hundreds of people to visit the 29 locations included on the Monopoly board. As usual, everybody entered splendidly into the spirit of the thing, wearing outlandish costumes, and surprising Londoners and visitors alike. We were fortunate to receive recognition from the Borough of Westminster. The dice were thrown by the Lord Mayor and Lady Mayoress to get the game under way. Sponsorship is still arriving and we hope to see a return of about £5,000.



JANE HAYMAN, organised another repeat event, the Mountain Express, which took place, *highly* successfully, in August. It is still slightly beyond me why hundreds of people are prepared to "yomp" over 40 miles of the Brecon Beacons, carrying 40lb packs, but thank heavens they are. The event generates thousands of pounds for ASBAH.

It was music to our ears to hear Major General Chiswell announcing, at the prize-giving ceremony, that the event is now in the HQ Wales calendar for future years and that the Army will give Mountain

Express their full support, particularly in the provision of radio communications, medical and other on-site back up.

This year, we expect to raise about £7,000.

These are just two examples of the many schemes which the Appeals Department have been working on and are continuing to devise. Full details of all our events are available from the Appeals Department at 22 Upper Woburn Place, London, WC1H 0EP.

JUDY KAY
Appeals Director

WHY WAIT?

Trust in North West Ostomy Supplies for unique service. One which offers probably the largest and most comprehensive ranges of Ostomy and Incontinence appliances and accessories all under one roof.

All products are stored under controlled conditions. Our policy is to provide you with a personal, confidential and specialist service, whether you are a private individual, Pharmacist or member of the Medical Profession.

The reliable source of supply for all Ostomy and Incontinence supplies and accessories.

- All leading makes stocked including: DOWNS, HOLLISTER, COLOPLAST SIMPLA ESCHMANN, FRANKLIN, DANSAC-COMBI, THACKRAY, SALTS, BIRKBECK TRANSLET and SQUIBB-SUGICARE.
- All types of barrier creams, plasters and deodorants.
- Orders despatched by return of post.
- Permanent Display Showroom of the most up-to-date appliances.
- National Health Service prescriptions dispensed.

NORTH WEST OSTOMY SUPPLIES

**The largest selection of Ostomy appliances-
All under one roof.**

North West House, 62 Oakhill Trading Estate, Worsley Road North, Walkden, Manchester M28 5PT. Tel: Farnworth (STD 0204) 709255 3 lines. Proprietor: Maureen A. Nuttall, SRN RSCN QN.

CLASSIFIED 'ADS'

The advertisement rate is:
 £2.25 for up to 30 words. £3.30 for 30-45 words.
 £4.50 for 45-60 words.

Please send remittance with your advert.

Please note that there is a 10% discount if you book six advertisements in advance.

Adverts for the next LINK (Nov/Dec) should be in by October 5. Send to the Editor Mrs Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

EXCHANGE & MART

Leisure Wear: White cotton Tee Shirts with green family symbol and words 'Support Spina Bifida'. Also Sweat Shirts in reverse colours. All sizes. Details from Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Holiday chalet. Pleasant semi-detached 6-berth holiday chalet, 150 yards from sea with easy access. Attractive site near shops. £8,250 fully furnished and well equipped.
 Details: (Cambridge Local Association), Mr D. Greasley, 2 Waddelow Road, Waterbeach, Cambridge. Tel: 0223 213823.

HOLIDAY ACCOMMODATION

BORTH, Nr Aberystwyth. 6-berth de luxe holiday home. Licensed site. Suitable for wheelchair users who live independently. Details: J. Carter, 1 Meadow Road, Craven Arms, Shropshire.

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

WINTERTON-ON-SEA, Nr. Gt. Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, take-away snacks, club room, play areas. Details: Mr R. Morris (0494) 32184.



ASBAH booklets, etc . . .

- Children with Spina Bifida at School*, Ed. P. Henderson, CB, MD, DPH. 50p
 - The Handwriting of Spina Bifida Children*, by Joan Cambridge and Elizabeth M. Anderson. . . . £1.25
 - Sex for young people with spina bifida or cerebral palsy*. £1.25
 - The Nursery Years* by Simon Haskell & Margaret Paull. 35p
 - Little Joe (A Grandmother's story)* by W. Foster. 50p
 - Life & Death—thoughts on bereavement*. 75p
 - Making our Way — individual experiences of young people with spina bifida & hydrocephalus*. £1
 - Information leaflets. 100 for £4.00
- Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindu, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.)

Please allow at least 30p for postage.

- Scottish Spina Bifida Association Booklets**
- The Spina Bifida Baby* by O. R. Nettles, McSP, ONC . 40p
 - Growing up with Spina Bifida* by O. R. Nettles, McSP, ONC 35p
 - Keeping Fit* by Jean M. Temple MCSP 10p
 - Self Help with Spina Bifida* by E. Wilson and E. Taylor. 10p
- Postage and packing is extra.
 Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW.

JOHN GROOMS HOLIDAYS

All facilities specially adapted for wheelchair users (family friends and escorts welcome)

Seaside Hotels: Llandudno and Minehead. (Bargain Winter Breaks for only £10 per day, incl. VAT)

Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton, Tenby, Looe, Maplethorpe and Camber Sands. Also in the Cotswolds. Ramps and other aids

Holiday Chalet: Near Skegness (Lincs)
 London Holiday Flat: London, N.4.

Motor Caravan: Hire for one or two weeks. Tail lift wheelchair, WC/Shower unit, etc.

Bungalow: In the heart of the Norfolk Broads
Canal Holiday: In adapted narrow boat.

For further details contact: John Grooms Holiday Department, John Grooms Association, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

BARNSELY
Mr B Fairclough,
2 Padley Close, Dodworth,
Barnsley, S. Yorks.

BEDFORD & DISTRICT
Mr I Pickering,
3 Mortimer Road,
Hillgrounds Kempston,
Bedford. Tel: Bed. 856992.

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mrs G Lanning,
23 Seaway Avenue,
Christchurch, Dorset.
Tel: Highcliffe 3255.

BRISTOL
Mr S Egan,
64 Rookery Road,
Knowle, Bristol 4.
Tel: Bristol 777942.

BROMLEY
Mrs M Nation,
13 Ash Road,
Green Street Green,
Orpington, Kent.

BUCKS & E. BERKS
Mrs R Storr,
2 Lower Icknield Way,
Aston Clinton, Bucks.
Tel: Aylesbury 631328.

BURY & BOLTON
Mrs B Day,
37 Lea Gate Close,
Harwood, Bolton,
Lancs, BL2 4AA
Tel: Bolton 53389.

BURNLEY & DISTRICT
Mr J Walton,
36 Fairways Drive,
Burnley, Lancs.

CALDERDALE
Mr A L Crowther,
12 Elm View,
Huddersfield Road, Halifax.
Tel: 0422 41497.

CHESTER & DISTRICT
Mr H G Collins,
10 Deanery Close,
Abbots Park, Chester.
Tel: Chester 382274.

DARLINGTON & DISTRICT
Mr C Kell,
18 Warkworth Avenue,
Bishop Auckland,
Co. Durham.

DERBY
Mrs J E M Clewes,
21 White Street,
Derby.

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton,
14 Leveson Road, Wednesfield,
Wolverhampton,
West Midlands, WV11 2HF.
Tel: Wolverhampton 738 724.

EAST ANGLIA
Mr P Grantham,
7 Ash Close, Downham Market,
Norfolk. Tel: D. Market 2200.

ESSEX
Mrs L Anderson,
25 Acacia Drive,
Upminster, Essex
RM14 2LJ.
Tel: Upminster 50449.

GLOUCESTERSHIRE
Mr Charles Stansroom,
20 Chiltem Road,
Church Lane,
Quedgeley,
Gloucester.

GRANTHAM & DISTRICT
Mrs J Asken,
88 Goodliffe Road,
Grantham, Lincs.
Tel: Grantham 60679.

GREENWICH
Mrs M Stredwick, Tower View,
17 Rusheymead, Brockley,
London SE4. Tel: 01-690 3086.

HAMPSHIRE NORTH, W. SURREY & S. BERKS
Mrs Selby,
The Old Police Station,
Woodbridge Road, Guildford.
Tel: Guildford 571736.

HAMPSHIRE SOUTH
Mrs E McKay,
39 Brighton Avenue,
Gosport, Hants. PO12 4BU.

HERTS. & S. BEDS.
Mr D Riseborough,
4 Sherborne Way,
Croxley Green,
Rickmansworth,
Herts.

HUDDERSFIELD
Mrs L Foster,
7 South Croft,
Upper Denby,
Huddersfield.
Tel: Huddersfield 863006.

HULL & DISTRICT
Mrs G D Brown,
233 Granbrook Avenue,
Hull. HU6 7TX. Tel: Hull 857165.

JERSEY
Mr George Baird,
15 Clos de Maitland,
St Clement, Jersey.

KENT
Mrs P F Parfett,
120 Mill Street,
E Malling, Kent.
Tel: 0732 841930.

LEEDS & BRADFORD
Mrs J Gibson,
Dale Croft, Fairway Crescent,
Haworth, Keighley,
W Yorks.
Tel: Haworth 44859.

LEICESTERSHIRE
Mr P Cusack,
31 Lime Grove, Kirby, Muxloe.

LINCOLN & MID Lincs
Mrs P Keyes,
Pinfold, Chapel Lane,
North Scafe, Lincoln.
Tel: Spalford 781.

LINCOLNSHIRE N.E. & S. HUMBERSIDE
Mrs J. Coulam,
ASBAH Centre,
Hainton Avenue,
Grimby.

LINCOLNSHIRE SOUTH
Mrs P Mason,
67 Boston Road,
Heckington, Sleaford.

LIVERPOOL
Miss B K Corkhill,
Tudor House,
Wood Lane,
Liverpool L27 4YA.
Tel: 051-488 0246.

LONDON, CENTRAL & NORTH
Mrs Christine King,
35 Oakfield Road,
Southgate,
London N14.
Tel: 886 7286.

LONDON N. EAST
Mrs Beryl Pierson,
18 Kingsley Road, E7.
Tel: 472 8605.

LONDON N. WEST
Mrs H Prentice,
37 Milton Road,
Hanwell,
London W7 1LQ.

LONDON SOUTH
Mrs S Cudd,
15 Woodvale Walk,
Elder Road,
W. Norwood, London SE27.
Tel: 01-761 2400.

MANCHESTER CENTRAL
Mr G Watson,
8 Bushnell Walk,
Manchester M9 2QH.
Tel: 061-795 0029.

MANSFIELD, WORKSOP & DISTRICT
Mrs E Freeman,
23 Melbourne Street,
Mansfield Woodhouse, Notts.

MIDLAND
Mrs D Britt,
14 Court Road,
Sparkhill, Birmingham 11.
Tel: 021-771 0371.

NORTH EAST (Northumberland)
Mrs E Grant,
27 Redwell Road, Prudhoe,
Northumberland.

NORTHAMPTONSHIRE
Mrs J Cockings,
57 Little Street,
Rushden, Northants.

OXFORDSHIRE
Mrs Pam Jarvis,
71 Woodfield,
Ruscombe, Banbury,
Oxon.
Tel: Banbury 58124.

PONTEFRAC T CASTLEFORD & DISTRICT
Mrs N Robinson,
4 Sandal Rise, Thorpe Audlin,
Pontefract WF8 3EX.

PRESTON
Mrs S Thompson,
34 Beatty Road, Southport,
Merseyside, PR8 6LB.

ROTHERHAM & DONCASTER
Mr & Mrs D Barringer,
21 Coppice Gardens,
Broom Riddings,
Greasbrough,
Tel: Rotherham 566686.

ST. HELENS & DISTRICT
Mrs N Maddocks,
324 Warrington Road, Rainhill,
Prescot,
Merseyside L35 9JA.

SALISBURY & DISTRICT
Mrs J Renshaw,
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA.

SHEFFIELD
Mr T Robinson,
3 Cecil Avenue, Dronfield,
Derbs, S18 6GW.
Tel: Dronfield 415523.

SHROPSHIRE
Mrs A Ashfield,
35 Trenleigh Gardens, Trench,
Telford, Shropshire, TF2 6RN.
Tel: Telford 612542.

SOUTHAMPTON & DISTRICT
Mrs H Vaughan,
6 Lumsden Avenue, Shirley,
Southampton, SO1 3EL.
Tel: Southampton 6636

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue,
Stoke-on-Trent, ST4 5JN.

STAINES, HOUNSLOW & DISTRICT
Mrs M McGuigan,
Jesolo,
Lea Croft,
Shortwood Common, Staines,
Middx. Tel: Staines 50854.

STOCKPORT
Mrs S Silver,
1 Brookside Avenue,
Offerton,
Stockport.

SUFFOLK
Mrs S Emmerson,
64 Cric'et Hill Road,
Felxstowe, Suffolk,
IP11 8LG.

SUNDERLAND
Mrs A Shepherd,
115 Holborn Road,
Sunderland.
Tel: Sunderland 283568.

SURREY
Mrs J Straker,
Squirrels Leap,
Woodfield Lane,
Ashted,
Tel: Ashted 72009.

SUSSEX
Mrs M White,
Averys, Rusper, Horsham,
Tel: Rusper 217.

SWINDON
Mrs S J J Trembling,
3 Church Place, Swindon.

TRAFFORD & SALFORD
Mrs J Robinson,
Moorefield Annexe,
Council Offices,
Crofts Bank Road,
Urmston, Manchester M31 1UD
Tel: 061-748 4000. Ext. 293.
Mornings.

WARRINGTON & DISTRICT
Mr S J Charlton,
36 Park Avenue,
Latchford, Warrington.

WESSEX
Mr T Poole,
123 Gerrards Green,
Beaminster, Dorset,
DT8 3EA.
Tel: 0308 862614.

WHITCHURCH & DISTRICT
Mrs D R Calder,
3a Bridgewater Road,
Whitchurch, Shropshire.

WIGAN, LEIGH & DISTRICT
Mrs L C Gill,
6 Beech Avenue,
Atherton,
Greater Manchester M29 9FA.

WIRRAL
Mrs S Keeler,
7 Church Road,
Upton, Wirral L49 6JY.
Tel: 051-677 1104.

WORCESTERSHIRE
Mrs Ann Cotter,
Mr & Mrs D Barringer,
37 Leigh Grove,
Droitwich, Worcs. WR9 9LD.
Tel: 0905 778925.

YORKSHIRE NORTH
Miss F M Seward,
45 The Paddock, York YO2 6AW.
Tel: 0904 798653.

WALES

LLANELLI
Mr P Williams,
8 Glasfryn Road,
Pontardulais,
Swansea, SA4 1LL.
Tel: 0732 841930.

MID-WALES
Mrs J Carter,
1 Meadow Road,
Craven Arms,
Shropshire.

NORTH WALES
Mrs E Boddy,
35 Gwynan Park,
Penmaenmawr,
Gwynedd.
Tel: 0492 622550.

SOUTH WALES
Mrs Brenda Sharp,
38 Redbrick Crescent,
Barry Island, S. Glamorgan.
Tel: Barry 735714.

SCOTTISH ASSOCIATION

Mrs Audrey Smith,
General Secretary,
190 Queensferry Road,
Edinburgh EH4 2BW.
Tel: 031-332 0743.

NORTHERN IRELAND

Mrs E I McDowell,
23 Dalboyne Park,
Lisburn,
Co. Antrim BT28 3BU.
Tel: Lisburn 6023.

Antrim
Mrs R Lynd,
2 Gortgorn Terrace,
Toomebridge, Co. Antrim.

Ballymena
Mrs F McNeil,
123 Broughshane Street,
Ballymena, Co. Antrim.

Belfast
Mr F D Hunter,
55 Wanstead Road,
Dundonald, Belfast.

Coleraine & District
Mrs L E McClure,
27 Tober Road,
Ballymoney, Co. Antrim.

Lurgan & Portadown
Mr B J P Byrne,
Hollyvale, Hollymount Road,
Laurencetown,
Craigavon, Co. Armagh.

Mid-Ulster
Mr R Stafford,
24 Kingarve Road,
Dungannon,
Co. Tyrone.

Newry & Mourne
Mrs M Grant,
7 Dora Avenue,
Newry, County Down.

Omagh
Mrs A Cochrane,
Bonnybrooke,
Public, Temple,
Co. Fermanagh.

OTHER LOCAL ASSOCIATIONS

Blackpool & Fylde
Mrs M Brammer,
9 Wolverton Avenue,
Blackpool.
Tel: 0253 911115.

Beeston
Mrs S S Goodfellow,
5 Cyril Avenue, Beeston.

Cambridgeshire
Mr R Wilkie,
Innisfree,
Mill Lane,
Hemingford Grey, Cambs.

Cannock & Walsall
Mr Ken Hall,
17 Wallhouse Street,
Cannock, Staffs.
Tel: Cannock 4847.

Chesterfield
Mrs K M Tomlinson,
23 Hatheron Close,
Brimington Common,
Chesterfield.

Consett & District
M Broadley,
15 Girvan Close,
Burnside, E. Stanley,
Stanley, Co. Durham.

Cornwall
Mrs Barbour,
Selsey House,
St Stephens Coombe,
St Austell, Cornwall.

Hillingdon
Mrs L A Christie,
8 Lonsdale Close,
Uxbridge, Middx. UB8 3BY.

Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor.
Tel: Chale Green 234.

Lancaster, Morecambe & District
Mrs M Dyson,
25 Royds Avenue,
Heysham, Lancs.

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Oldham,
Lancs.
Tel: 061 652487.

Somerset
Miss June Roberts,
1 Ilford Court,
Wiltshire Close,
Taunton.

Teesside
Mr J Gray,
Marches Centre, Tollesby Road,
Middlesbrough, Teesside.

Please will all local Secretaries who want their telephone numbers included in this Directory get in touch with LINK Editor: Mrs S. Gearing, at National Office: ASBAH, 22 Upper Woburn Place, London WC1H 0EP.