

Link

Association for Spina Bifida and Hydrocephalus/ASBAH

May/June 1986

Issue Number 104

30p



Association for Spina Bifida and Hydrocephalus (ASBAH)

22 Upper Woburn Place, London WC1H 0EP

Registered Charity No. 249338 TEL: 01-388 1382/5

Patron: HRH The Duchess of Gloucester

Chairman: Mr R. R. Mackenzie **Hon. Treasurer:** Mr A. K. Stewart-Roberts

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

Executive Director: Miss Moyna Gilbertson, MCSP, FBIM **Finance Director:** Mr Derek Knightbridge, FCCA

Appeals Director: Mr Douglas Jack

Services Director: Mrs Barbara Newman

Public Relations Manager: Mrs Madeleine Legg, MIPR

Education, Training & Employment Co-ordinator: Mrs Denise Dunning

Information Officer: Miss Beverley Holland, BA, MIPR

Fieldwork Co-ordinator: Mrs Teresa Cole, MICA

Accommodation Officer: Miss Carolyn Smith (from June 9)

LIFT (Young ASBAH) Organisers:

Miss Ann Monaghan; Mr Andrew Neale

Manager at Five Oaks, Ilkley, Yorks:

Miss Joan Pheasant, NNC

Development Officer at Five Oaks:

Mr Paul Cooper BA (Hons)

Disabled Living Advisers:

Miss Mary Barton, MCSP; Miss Mary Small, Dip OT, SROT;
Miss Clare Michelmores, RGN, HV; Mrs Leonie Holgate, M

Administrator: Mr Paul Dobson, BA (Hons), Grad. IPM.

Link Editor: Mrs Susan Gearing

ASBAH Publications

All available from National Office.
Cheques payable to 'ASBAH'

Children with Spina Bifida at School (1985)
Ed. P. Henderson 95p

Five Oaks leaflet. Free

Young People with Spina Bifida and/or Hydrocephalus —
Learning & Development (1985)
Leonie Holgate £1.60p

Fact Sheets up to 10 copies free

The Handwriting of Spina Bifida Children (1979)
Joan Cambridge, Eliz. M. Anderson £1.60p

Translations of fact sheets are available into Bengali, Gujarati,
Hindu, Punjabi and Urdu, and into Welsh.
Please send at least 30p postage.

Spina Bifida and You — a Guide for Young People (1985) £3.50p

Films and Slides

Sex for Young People with Spina Bifida or Cerebral
Palsy (1984) £1.75p

Appeal for ASBAH (for hire) £4.00p + 60p VAT
16mm colour film (8 mins)

The Nursery Years (1983)
Simon Haskell, Margaret Paull 60p

Living with Spina Bifida
Slide sets and notes (12 slides) £7.00 + 75p VAT

Life and Death — thoughts on bereavement (1983) 75p

Magazines

Making our Way — individual experiences of young people
with Spina Bifida and Hydrocephalus (1984) £1.20p

LIFT — for members of LIFT (young ASBAH) Free

Your Child with Spina Bifida
Prof. J. Lorber (1981) 60p

Causeway — for contributors to ASBAH's work Free

Your Child with Hydrocephalus
Prof. J. Lorber (1981) 60p

LINK SUBSCRIPTION

Booklets/leaflets

General leaflet. Free
Housing: general advice for young people. Free
60p for professionals

UK £3.30p

Europe and Overseas Surface Mail £4.80p

Air Mail £10.80p

For payments other than in sterling add the equivalent of £3.

All prices include post and packing.

* Except in the case of LINK all the above prices apply in the UK
only. Overseas rates on request.

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.

Editor's Note

The successful passage through the House of Commons of the Disabled Persons Bill was indeed a ray of sunshine in the midst of a gloomy April. It seems that disabled people will at last have their community needs properly looked at as well as their rights to proper assessment and representation.

The positive support given to the Bill by all parties indicates the recognition which is finally being made of the needs of disabled people. ASBAH is particularly pleased that provision is being made for the proper assessment of the future needs of a young person well before he or she leaves full time education. All too often young people leave school without adequate provision for their future being made.

We hope that the Government will not use the costs of implementing the provisions of the Bill as an excuse for delaying Royal Assent. The more disabled people are involved in their assessments, the more the services they receive will be cost effective. (For a summary of the Bill see page 5.)

★ ★ ★

LINK is embarking on something new — the promotion of a LINK readers' holiday to Florida in the Autumn of 1987.

Hopefully it will be possible to make up a party of 70 people — LINK readers from all parts of the country. They will have a holiday of a lifetime, and the opportunity of making new friends.

If you want to know more turn to page 4.

Sue Gearing, Editor

On the INSIDE

MAIN FEATURES

- 8 **LINK visits the Isle of Wight**
- 25 Struggling with grief — following termination of pregnancy
- 16 **LONDON for disabled visitors**



IN THE NEWS

- 5 **Disabled Persons Bill**
- 5 Invalid Care Allowance
- 23 Prizewinning wheelchair bag and other **Newslines**

LIFESTYLE

- 28 Personally speaking — views from both sides of the Atlantic

LEISURE

- 4 **LINK READER'S HOLIDAY TO AMERICA**



- 14 Youth Hostelling
- 15 **Hobbies** — collecting cigarette cards
- 19 **Reading Matter**

GENERAL

- 7 **Letters**
- 12 Sheila completes the London Marathon and other **Round-up news**

PLUS

- 21 **Index** of LINK articles in 1985
- 27 **Meetings and Conferences**
- 31 Classified Advertising.
- 32 Directory of Local Associations

SPECIAL INSERT IN THIS ISSUE — GUIDELINES ON EMPLOYMENT AND TRAINING.

COVER PICTURE

You must all know the person on the right — **Steve Davis**, of course. With him is 11-year-old **Simon Fricker** of Bromley, Kent. He had a day he will never forget in early April when the "Jim'll Fix It" programme fixed it for him to play Steve Davis. Simon, who is quite severely disabled with spina bifida and hydrocephalus, proved to be very competent at snooker. A special table which was made for him for the programme, was later presented to Simon as a keepsake.

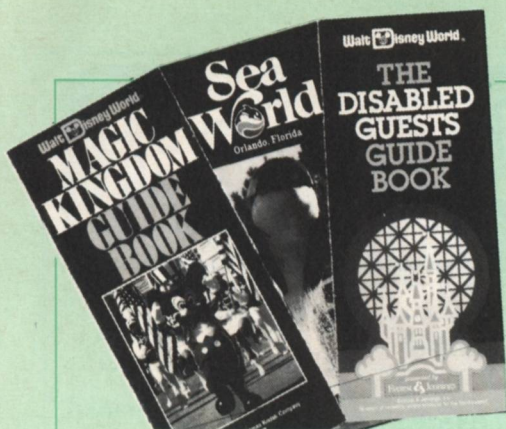
Photo: BBC

Link

is published by ASBAH (The Association for Spina Bifida and Hydrocephalus)

Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the next issue is June 5. Send to the Editor at National Office.

© Copyright here and abroad of all editorial content in LINK is held by the publishers, ASBAH. Permission is required from the publishers before any material is reproduced.



Especially for LINK readers
Two centre holiday in



FLORIDA, USA

16 DAYS IN OCTOBER 1987

To include

- ★ 3 days Disney World
- ★ 1 day Cypress Gardens
- ★ 1 half day Busch Gardens, Tampa
- ★ 1 day Sea World
- ★ 1 day Circus World
- ★ 1 day NASA Space Centre
- ★ 3 days at Clearwater Beach

LINK is joining forces with a leading travel service agent, Panovista, to organise a first ever holiday for readers.

We felt that local associations might welcome the opportunity to get together and enjoy a well planned, and tried and tested holiday in the States. It is a holiday of a lifetime. A local association might like to help send two or three of its younger members, or alternatively whole families might be interested.

The idea has been prompted by the success of a holiday organised by Panovista in October 1985 for 68 members of Sunderland ASBAH, including 15 people in wheelchairs. The LINK holiday will be very similar.

Chairman of Sunderland Association, Mrs J Shepherd, said she couldn't speak too highly of Panovista or the holiday. "They took great pains to see that everything was properly planned and facilities were accessible. We had no problems. It was a really wonderful holiday. We'd love to go again."

She also said that the holiday had been a wonderful way of uniting members and bringing the association together. This could also work on a national scale, giving ASBAH members a chance to meet others in a different part of the country, to make new friends.

Panovista wish to restrict numbers on

the LINK holiday to about 70 so that they can give a personal service.

This is a first announcement of the holiday so that Panovista can gauge the kind of response there is likely to be. If you think you, your family, or local association members are likely to be interested please will you fill in the form below. It puts you under no obligation. More details will then be sent later.

Flights by British Airways will be arranged from Manchester, and also from Gatwick, provided there is sufficient response from the South.

The cost has not yet been fixed, but is likely to be about £700 per adult, £450 per child.

This price includes everything listed below, except for food, which is very reasonably priced.

Included in the 15 night package are all the attractions listed at the top of the page plus:

- ★ COACH TRANSFERS at pre-arranged picking up points, to MANCHESTER AND GATWICK, and RETURN
- ★ FLIGHTS by British Airways 747 to ORLANDO and Return, & Airport tax
- ★ ALL COACH TRANSFERS to

and from hotels and attractions

- ★ 10 NIGHTS accommodation at the NEW CONTINENTAL ROYALE HOTEL, near International Drive, Orlando. Conveniently situated hotel. Large swimming pool, restaurant. Air conditioning in all rooms, private bath, WC and shower, colour TV and telephone. Lifts to all floors. Each room has two double beds

- ★ 4 NIGHTS accommodation at the CARIBBEAN GULF HOTEL, Clearwater Beach on the Gulf of Mexico. 5 star hotel with superb beach side position. Bay or beach views. Free inhouse colour TV movies, bath, shower, WC. Air conditioning, Lifts to all floors. Each room has two double beds or 1 king size bed. Choice of hotel restaurants, entertainment lounge and disco, buffet at the hotels poolside

This is a wonderful spot to enjoy three clear days either relaxing on the beach or sightseeing locally

- ★ 6 STAR FLIGHT VALUE FREE: inflight movies and stereo, flight bag, duty free vouchers, bar service during flights, flight pack, wine with meals

During the stay in Orlando and Clearwater there will be other optional tours available.

To: LINK Readers Holiday, Panovista Travel, 78 Sea Road, Fulwell, Sunderland SR6 9DB.

Please would you send me, without obligation, further details about the proposed LINK readers' holiday to Florida.

There may be..... person(s) interested in the holiday (please give approx. numbers)

We would prefer to fly from Gatwick, Manchester (please cross out as appropriate)

Name:

Address:

If you need further information about the holiday please contact: Mr J. G. Brown at Panovista. Tel: 0783 494444 or Mrs Sue Gearing, Editor LINK. Tel: 0934 862279.

THE DISABLED PERSONS' BILL

THE DISABLED PERSONS' BILL sponsored by Tom Clarke, MP for Monklands West, has successfully completed its passage through the House of Commons following its Third Reading on April 11. The support given by all parties to the Bill is indicative that recognition is at last being given to the rights and needs of the 5.5 million people with disabilities in the UK.

A move towards equal status

The main provisions of the Bill are:—

1. *The right of a disabled person to appoint a representative to act on their behalf when dealing with local authorities with regard to the provision by that authority of any welfare services. The representative will also be able to accompany the disabled person to any meeting or interview in connection with the provision of social services, and will also have access to any necessary information and documents.*
2. *The social services department is to be informed not later than nine months before the presumed date that a disabled child is to cease full-time education so that an assessment can be made as to future needs.*
3. *Hospitals will be required to give an assessment of particular needs, before discharging people who have received in-patient treatment for a mental disorder for at least six months.*
4. *Local authorities will have to determine the assistance needed by carers to enable a disabled person to remain at home. The carer, as well as the disabled person, may also request an assessment.*

Parents of children with spina bifida and/or hydrocephalus know well the worries of what will happen when their child leaves school with no adequate provision being made for their future needs. Hopefully this Bill will end this problem.

This Bill is the first real attempt since the 1970 Chronically Sick and Disabled Persons Act to try to meet the needs of the growing numbers of disabled people and those involved in their care. The current policy of 'Care in the Community' has meant an increasing burden on informal carers, many of whom are themselves sick or tired; their needs are at last recognised, by giving them the opportunity to seek help before a crisis develops.

There is still a long way to go before disabled people enjoy the same status as the able-bodied, but perhaps, at least this is a beginning.

Invalid Care Allowance

ON April 22, 1986, the Advocate General, an official of the European Court of Justice in Luxembourg, delivered his opinion in favour of Mrs Jacqueline Drake. This brings a step nearer the campaign for married and co-habiting women to claim the £23 per week Invalid Care Allowance if caring for a disabled or elderly relative.

Mrs Drake, 42, lives in Worsley, Manchester. In March 1984 she was forced to give up work in order to care for her 69-year-old mother who suffered from severe senile dementia. She was awarded Invalid Care Allowance in March 1985 following an appeal tribunal hearing which decided that the rule which prevents married and co-habiting women from claiming Invalid Care Allowance no longer applied.

The DHSS appealed against the decision, and the case was heard at the European Court of Justice in Luxembourg on January 22 this year.

More than 100,000 women are likely to benefit if, as expected, the final judgment, expected in June, agrees with the Advocate General's Opinion.

TWO NEW ASBAH LEAFLETS

ASBAH
Association for Spina Bifida and Hydrocephalus

FIVE OAKS

Activity and care centre
Ilkley, West Yorkshire.



ON EQUAL TERMS

the work of
ASBAH

THE ASSOCIATION
FOR SPINA BIFIDA
AND HYDROCEPHALUS

ASBAH's publicity department has produced two attractive new leaflets.

One is about Five Oaks and gives information about the role and activities of the centre, and the other is a general information leaflet about the work of ASBAH.

Individual copies are free. There will be a small charge for bulk orders.

Available from Beverley Holland, Information Officer at National Office.

Caring for the Severely Disabled

Do you care for someone who is severely disabled and feel that your views don't receive enough attention in LINK? If so, please do write to me as soon as you can, letting me know the kind of articles, information, views, you would like to see.

There seems to be a feeling of frustration, that too often LINK tends only to highlight those who are becoming independent and achieving.

Sue Gearing (Mrs) Editor.

MR. DOWNEY OF

AHOGILL FELT ROOFING COMPANY

WISH **ASBAH** ALL
SUCCESS WITH
THEIR
WORK

**FELT ROOFING AND
BUILDING WORKS**

16 CULNAFAY ROAD
TOOMEBRIDGE
CO. ANTRIM
N. IRELAND

TEL: 0266-871587

THE TELE-TRADING GROUP OF COMPANIES

offer best wishes and
full support to **ASBAH**

TEL: HIGHCLIFF (04252)

78746

TELEX: 41301

HIGHCLIFFE HOUSE,
111-413 LYMINGTON ROAD,
HIGHCLIFFE-ON-SEA,
DORSET

Sincerest Best Wishes
to **ASBAH**

MICHAEL THORNE CONSTRUCTION

Specialists in Steel - Framed
Buildings and Concrete Works

TEL: LAPFORD (03635) 418

COLDRIDGE
CREDITON,
DEVON
EX17 6AS

*BEST WISHES AND A
PROSPEROUS NEW YEAR
FROM*

R. J. ABBINNETT & SONS

DECORATING CONTRACTORS

SPECIALISTS IN
DOMESTIC &
COMMERCIAL
DECORATING

FOR COMPETITIVE RATES
RING

**WATERLOOVILLE
267532**



ROY DOUGLAS BRACE

Article — LINK Jan/Feb '86

This new exciting system of bracing limbs in opposition was used to my knowledge as early as 1969 at The Chailey Heritage, Sussex.

The design was brought to me by an engineer from the Midlands who became interested in rehabilitation as he had a disabled child. We were all very impressed and worked on this system for reciprocal gait with a lot of enthusiasm. In 1974, however, we abandoned this as we came to the conclusion that to make it work effectively you needed hip flexors and hip extensors, and if you had these you did not need to brace above thigh level.

At the same time, David Scrutton of the Newcomen Centre, Guys Hospital, was working on a very similar system using exactly the same cable connection for reciprocal gait. David's polyplaner was originally intended for use with cerebral palsy to improve the pattern of gait. It was also used for ambulation in spina bifida but with little success. The last orthosis using cables in my workshop was made in 1979 for a boy with spinal muscular atrophy. It was very similar in design to the Roy Douglas

brace. It was not received with any enthusiasm by the physiotherapists and was little used.

May I offer a word of caution? Your article is somewhat more factual than the TV documentary, although you do give the impression that this item is only available from one contractor in the UK. This documentary has confused many parents of disabled children. I have been approached by several, asking for these "electrically powered calipers" and many whose children walk very well in above-knee and some with below-knee orthoses who think they will be improved by bracing to mid-thoracic level which is nonsense, but they tend to believe a TV film rather than take the advice of medical and paramedical staff who have had experience over many years.

There is nothing magical or new about connecting one leg in opposition to the other by cables on a parallelogram system. Neither does it provide any power to a paraplegic. It is most certainly not the only form of orthosis for reciprocal gait in high level paraplegics. I have many children with severe muscle disorders who are able to walk with a reciprocal gait without the aid of crutches or other walking aids. A

Letters

thorough multi-disciplinary team assessment should be made of any disabled person before a prescription is made out for any orthosis.

In conclusion, I should like to wish every success to the Roy Douglas programme and any other form of research for rehabilitation of the severely handicapped. I am grateful that the whole subject of reciprocal gait has been brought to prominence. Too many people are content to go on producing the same old orthoses even though they know that high-energy consumption gait is not possible with conventional orthoses once a child reaches a certain age and weight. It has made me look back at our research of 1969-74 and re-examine the joints and cables used to see if they can be improved and used successfully.

John Florence
Orthotist
Orthotic Workshop
The Chailey Heritage
Chailey Sussex

SPEED WELL with SUPAKART



More information from . . .

Berkshire County Council, (Speedwell Enterprises), Freepost,
SLOUGH SL1 3BR. Telephone (0753) 72249

The Mobile Aid with children in mind.

- ★ Suitable for ages 6 – adult
- ★ A battery operated vehicle
- ★ Hand controlled
- ★ Top speed 3 miles per hour
- ★ Range approx. 6 miles
- ★ Complies with Invalid Carriage Regulations.

LINK recently looked at the situation facing those with spina bifida and hydrocephalus in the North. Continuing this series we now look at a different part of the country — the Isle of Wight.

THE Isle of Wight is Britain's smallest county — an irregular diamond measuring 16 × 11 miles at its widest point — and small in this case does seem to mean beautiful. The islanders with spina bifida and hydrocephalus and their families appear to be benefitting from living in a caring and close-knit community.

Out of a population of 120,000, the island has about 2,000 disabled people. The interest of those with spina bifida and/or hydrocephalus is watched over by the Isle of Wight ASBAH.

Although not affiliated to National ASBAH it is a very active group. Formed 19 years ago, it has managed to achieve a great deal to help its 26 member families and other people on the island with spina bifida.

"When anyone with spina bifida or hydrocephalus is born here the news spreads like wildfire and we soon hear about it and are able to offer help as appropriate" said Anne Axford one of the Committee members who has adopted Gary a 3-year-old with spina bifida and hydrocephalus.

Help comes in many forms. It can mean talking to the mother of a new born baby or providing transport for an older person who is finding it difficult to get out.

Mrs Axford admits that she is one of those people who is not afraid to stand up for her rights, but adds that it is also true that families who do not shout on the island, do not get missed out either: the community grapevine soon gets to work. "We hear about them — or the social services do — and are able to offer help", she says.

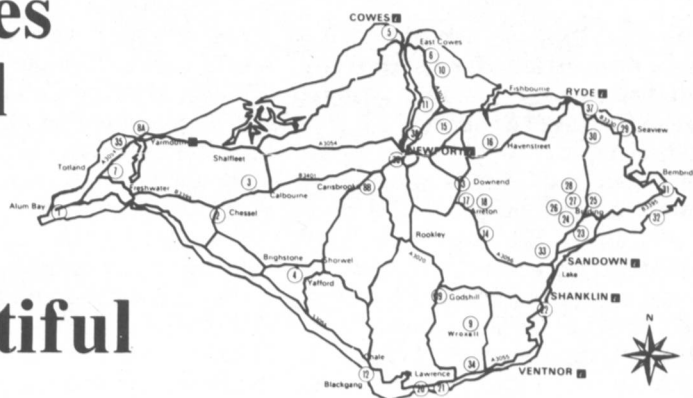
She praised the team work of the different professionals involved with the care of the disabled. Case conferences are made easier because each of the professionals knows the person concerned.

The social services employs a peripatetic social worker, Alice Turner, a familiar and much liked figure on the island, who regularly visits every disabled child and gets to know them well.

There are a couple of families with new-born spina bifida babies on the island, and two toddlers aged 2½ and 3 years, but the largest group is teenage. There was a big gap from the mid 1970's with very few babies with spina bifida and/or hydrocephalus surviving.

There are some older members too,

Isle of Wight proves small can be beautiful



Young members enjoy a Christmas party

notably Mrs Pat James who is in her forties. She has an adopted son and strapping 15-year-old twins of her own. She is well known for standing up for her rights. Mrs Margaret Spencer is 74, and recently featured in LINK as Britain's first spina bifida great grandmother. (Read more about both on these pages.)

There are six islanders with hydrocephalus only, and interestingly 10 of the 26 members with spina bifida and hydrocephalus were born in the Cowes area — which is by no means the area of highest population.

St Mary's Hospital can cope with basic hospital care, but if operations are necessary at birth or if a valve blocks this means a ferry ride to Southampton, or in an emergency, a helicopter airlift.

Schooling for island children who are disabled is also well catered for, particularly in the early years; at Medina School for those with more severe handicaps; and at Watergate School for those with minor learning problems.

Watergate School is popular with most

disabled people because of its hydrotherapy pool.

Many of the older children with spina bifida and/or hydrocephalus leave the island for secondary schooling. Debbie Hendy, for example, boards at Treloar College in Hampshire.

The family feeling within the island's ASBAH, and its apparent success, is largely due to the strong, active committee and in particular to the man at the top, Secretary and Treasurer, Derek Sprake. He is known, it seems, as 'the spina bifida man'.

"I don't know where we would be without him" commented Pat James.

Derek doesn't have a disabled child of his own but was called in to help 15 years ago. "It won't take much of your time" he was told! Now he spends many hours of his spare time working for the Association — and for other community ventures. Under his leadership ASBAH has developed a strong identity on the island.

The Association is involved with fund-raising, with outings and social activities. It owns a holiday chalet on a site near Freshwater which is very popular with ASBAH members up and down the country.

The Association has a firm rule that the money it receives should not just sit in the bank, but be used, as intended, for members. It is proud of its Loan Scheme.

"It's a way of rotating the money we get in, and using it for the benefit of members" said Mr Sprake. "We lend money to members for expensive capital items, such as a car or for adaptations, etc. We charge a 2% flat rate and we find that members really prefer this to being given money which seems too much like being given charity.

"They know they have to pay it back and they do. In the eight years we must have loaned £25,000-£30,000, and have only lost £28, and even that was unintentional" he said.

Included with the loan is life assurance cover. "I began to feel this was a bit of a waste of time, until fairly recently, when one of our members to whom we had loaned money died and with the life assurance not only was the loan paid off but there was a sizeable sum left over which proved very useful to this particular family" he said.

The Association also has a Handicapped Members Fund, which gives grants to members for particular items. It was used recently to help two of the young adult members who were setting up home. "We helped them to buy equipment for their new homes, which they couldn't have managed on their own" said Mr Sprake.

The committee is trying to encourage more get-togethers. It is important that members are kept in touch with what is going on and the Association remains aware of their problems and needs.

Derek Sprake writes a regular newsletter, and Mrs Joyce Swaney, Vice-Chairman, gets to see each member at least once a year as she visits each on his or her birthday, taking a card and a gift from the Association. This tends to be cash, but recently when she heard of one member's real love for roses, she went out and bought several of his favourite rose bushes.

Committee member, Phyllis Haldenby represents the Association on the Federation of Societies for the Handicapped which looks after the interests of all the Isle of Wight's disabled residents.

Recently the Vectis Association was formed to aid and inform disabled motorists living there and to represent them, for example in negotiations with the ferry concessions and facilities. Ensuring that the travel facilities of the islanders don't suffer because of the thousands of summer tourists who flock in by ferry and hovercraft is quite a difficult problem.

The summer months do present difficulties for residents; travelling round the island becomes difficult on congested roads and parking is at a premium. Unfortunately there is no special travel scheme for the disabled on the island, such as Dial-a-Ride.

Life for any disabled person is usually far from easy and this is true, even for those living on 'The Happy Isle' — as the tourist brochures call it. They still have to fight for their rights, for access, equal opportunities, suitable facilities. But the climate there is much easier, in more ways than one, than in other parts of the country, and does give many a chance of enjoyment and fulfilment, particularly if they are under the wing of a strong, caring group like the Isle of Wight ASBAH.

Go-ahead for Centre plan

AFTER thinking and talking about it for 15 years the Isle of Wight has agreed to go ahead and build its own multi-purpose centre and workshop for the disabled.

The decision to proceed was taken this Spring, due in no small part to the enthusiasm and support of the new Director of Social Services, Bill Davison.

The project is being backed by all the disablement organisations on the island, including ASBAH. What started out as a proposal to have a workshop has now grown into a much bigger venture which will benefit the whole island community, not only those with disabilities.

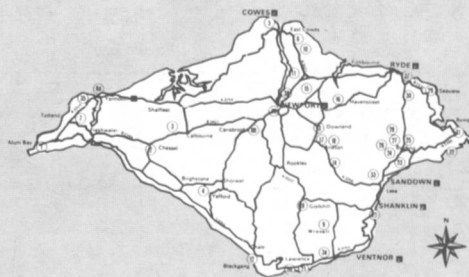
Work should start in January 1987, and when completed the centre will open every day and evening and provide all kinds of social and recreational facilities — a bar,

restaurant and coffee room, rooms for leisure activities and hobbies. There will also be a computerised information service for the disabled and special rooms put aside for consultations, trying equipment and aids.

A workshop will provide training for employment and there will be an arcade of small shops selling crafts and cottage industry wares. It is hoped that disabled people will be employed at the centre, and the aim is to attract disabled and able-bodied people of all ages from all over the island.

A great deal of fund-raising has already taken place and will continue with renewed vigour now that a date had been set.

The Isle of Wight ASBAH feels that the centre will be a great asset, particularly to many of its teenage and young adult members of whom there are a growing number.



Pat believes in fighting for a better deal

IT'S all too easy for a disabled person to give up asking, especially when the answer is so often 'no', says Pat James, but "We have to keep on".

Pat who is in her forties has spina bifida and is in a wheelchair. She gets very cross about lack of facilities, restrictions and barriers which impede the freedom of people in wheelchairs.

She managed to get ramps installed at Sandown station, simply by asking, and ramps in Sandown town itself, by asking and enlisting the help of the Mayor, Miss Heather Humby. Recently she was successful, after quite a lengthy and vociferous campaign, again with Miss Humby's help, in securing the removal of a barrier in an underpass.

She writes constantly to the local press and local radio, and manages to keep cheerful despite difficult home circumstances.

Her husband, Dennis, is disabled by arthritis and back trouble, and they rely on their eldest adopted son Danny to run the house.

"He is our life blood, but I feel guilty about the way in which we put on him" she said. Clearly Danny hasn't been able

to develop a life of his own. He is a very talented artist — and turned down a place at Art College when younger. Art is his major form of relaxation.

Pat and 'Den' have strapping twin sons, Peter and Colin aged 15.

It's not easy to live any kind of life when it's impossible to get around. Pat can't propel herself; her husband can't push her and Danny is often too busy. That was why the electric wheelchair which ASBAH on the island offered to Pat proved to be her pass to freedom.

But unfortunately her freedom was short-lived. It appears that the chair has given a great deal of trouble and now sits immobilised in Pat's garage. LINK is getting in touch with the manufacturer to see if they can throw any light on the problem — so watch this space for further developments!

Footnote: Since visiting the island LINK has heard that Pat's troubles were reported on Radio Solent and were heard by the Rotary Club. They have come to her rescue and are offering to lend her a spare electric chair until such time as her own can be put back on the road. The grape vine certainly works on the island, doesn't it!

Our *first* Great 'Grandma' tells her own story

BRITAIN'S first spina bifida great grandmother (well we think she is) is Mrs Margaret Spencer from West Cowes in the Isle of Wight. She is very proud indeed of her great granddaughter, Tanya, who was born in Nottingham in the Autumn ... the daughter of Mrs Spencer's grandson.

Her family has been 74-year-old Mrs Spencer's greatest joy and what has kept her battling through a far from easy life. She was brought up, the second of four girls, in a Leicestershire village where spina bifida was unheard of. "My father used to carry me round on his back" she said.

"From an early age hair started to grow across my back, about the time I began to crawl. My mother was embarrassed by it and cut it off. I remember one day the doctor called to see us — on horseback — and told her that the reason I didn't walk was that cutting the hair had sapped all my strength. So she had to let it grow again.

"It was so long I had to plait it. The funny thing was that the hair on my back was fair, whereas the hair on my head was very dark. The doctors said that I must have been one of twins and was carrying the other baby's hair, but my mother — who gave birth to me herself with no midwife — insisted that I was the only baby".

Margaret eventually started to walk and wore high leg boots. She was sent to the village school where nobody seemed to make a big fuss about her handicap, but where, she says, she came up against very unsympathetic treatment from the headmaster. She said he made her feel she was useless and a burden.

From the quiet backwaters of Leicestershire the family moved on when Margaret was 13 and she was pitched into the industrial life of Manchester.



Margaret Spencer and her great grand-daughter, Tanya.

Eventually she was enrolled as an apprentice in the clothing industry with a Manchester firm, Barlow and Jones.

"I was very small and thin with long plaits and big boots. I hated it there, but somehow I managed to stay to complete my apprenticeship — 2½ years. I only earned eight shillings a week during all that time".

'Young Maggie' had to cope with 1,000 steps up to the factory each day and had to get used to carrying huge textile bales. "I didn't dare tell my employer that I was disabled. I would have lost my job".

The training was rigorous and thorough, but she stuck it and showed great talent for the trade. She ended up as a very competent seamstress producing top quality quilts and bedspreads and fine curtains — 'swags and tails'.

The apprenticeship completed, she left as soon as she could, and after one miserable job found herself with another Manchester firm, Rogers and Hamblin.

Here she was highly respected and well treated, and over the years she worked her way up to being forelady in charge. She made magnificent bedspreads and eiderdowns, the kind of work rarely seen today, with pleating and tucking and embroidery all done by hand.

The happiness of her working life contrasted with a bitterly unhappy marriage. She lost a baby son at 15 months with pneumonia, and eventually divorced her husband for cruelty and was

left to fend for herself and her daughter, Margaret. She refused any financial help from her husband and worked long hours to support Margaret at school, battling to keep her daughter with her and to give her a good education.

She left Manchester to live near her mother in Nottingham, and later remarried and moved with her second husband to the Isle of Wight. Unfortunately, he died after only four years but she has remained on the island working in the soft furnishing trade for Ryde Furnishers until she was 62. She made all manner of beautiful home furnishings for many of the larger homes on the island.

Her daughter Margaret became a successful children's dress designer and married and had two sons, the youngest of whom, Tony, recently married a Belgian girl and they had Margaret's first great grandchild, Tanya. Margaret's eldest grandson, Paul, is at University.

Margaret says she has not suffered many problems with her handicap except in the last few years. She has damage to her pelvis and this is giving her very great pain. She is finding it more and more difficult to move about.

She was recovering from flu when LINK visited her, but nevertheless despite feeling under the weather, she managed to talk cheerfully about her life and her family.

Our best wishes to Margaret for a speedy recovery.

WHY WAIT?

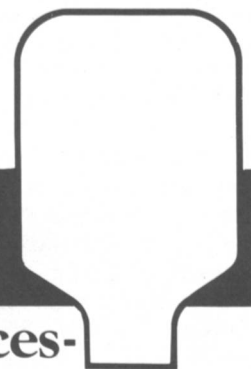
Trust in North West Ostomy Supplies for unique service. One which offers probably the largest and most comprehensive ranges of Ostomy and Incontinence appliances and accessories all under one roof.

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.

Best wishes to ASBAH from: — **TENTER TRAVEL**

for efficient fast and courteous service together
with good value for money.

**MAKES US UNBEATABLE
SO DON'T DELAY
RING US TODAY**

**NEW YORK from £235 return
SYDNEY from £638 return
JOHANNESBURG from £554 return**

Contact: Mr. Peter Ling
4-6 Tenter Ground, London E1
Tel: 01-377-5030

HAULAGE INSURANCE

- **VERY COMPETITIVE
QUOTATIONS**
- **CREDIT SCHEMES
AVAILABLE**

BROWN WILLIAMS & PAINE

FELIXSTOWE (0394)
285494

The FIORINO HI-LINE

The High Quality LOW COST SOLUTION



**£5295
ON THE ROAD
*DELIVERED TO THE
DOOR (UK ONLY)**

- | | |
|---|--|
| ★ WINDOWS BOTH SIDE
AND FRONT | A FIAT MOTOBILITY
APPROVED AGENT |
| ★ BUTTONED DRAYLON
SIDES AND CARPET
INTERIOR | ★ FOLDING
ATTENDANTS BENCH
SEAT TO CHOICE |
| ★ TELESCOPIC RAMPS
FOLDING UNDER CHAIR | ★ FULLY ADJUSTABLE
CLAMPS AND INERTIA
SEAT BELTS |
| ★ FULLY WINDOWED
RAISED ROOF AND
ELECTRIC WINCH
OPTIONAL | ★ SUNROOF + QUALITY
RADIO CASSETTE |

GALWAY SMITH OF HUDDERSFIELD LTD

4 Queensgate, Huddersfield HD1 2UW

Tel: John Irving 0484 548111



Local Association Round-up

Greenwich

SHE DID IT: Eighteen-year-old Sheila Gwatkins of Lewisham, South London, (featured in LINK Nov/Dec 1985) achieved her great ambition and completed the London Marathon. Sheila was the youngest competitor and, we believe, the first competitor with spina bifida to complete the course. She was cheered on by friends and members of Greenwich association as she passed the finishing line — 5 hours 20 minutes after she started.

Local businessman Peter Carnham read in the South London Mercury about Sheila's great ambition to raise money for a sports wheelchair and take part in the marathon. He bought the chair for her and promised her £1,000 if she finished the course. He was true to his word and has already handed over the money to Sheila. She also raised a good deal of money herself through sponsorship, to be given to Greenwich ASBAH and Charlton Park School.



Happy birthday to ASBAH's first shop see "Southampton"
Photo: Southern Evening Echo.

Was she tired after her efforts in the marathon? . . . Shortly after arriving home, she had freshened up, changed and was out again to attend a meeting of the Disabled Christian Fellowship at Devonshire Drive Baptist Church in Greenwich. Next morning she was up at 6 am, had a shower and breakfast and was off to college as usual!

Sheffield

THE MUCH coveted guiding award, the Star of Merit, has been awarded to 13-year-old Karen Robinson of Sheffield — daughter of Executive Committee member Tim Robinson and

his wife Frances. Karen, who is a member of the 3rd Dronfield (St Andrew's) Company, recently had to undergo a very serious operation on her back, and faced it with great courage and cheerfulness.

The award was made by the Derbyshire County Commissioner, Olive Robinson (no relation!). Karen is only the second person in Dronfield to be awarded the Star of Merit as far as anyone can remember.

Staffordshire

CHRIS Adams and Nigel Longmore from Biddulph Air Training Corps, Stoke-on-Trent, climbed to the top of the forbidding bare rock, the Old

Man o' Mow, where they perched for 48 hours, exposed to all weathers, to raise £450 for Staffordshire ASBAH.

Southampton

SALES FORCE: Shops Organiser, Margaret Gillmore (above) and helpers celebrate the first birthday of ASBAH's first charity shop at the Bell in Southampton.

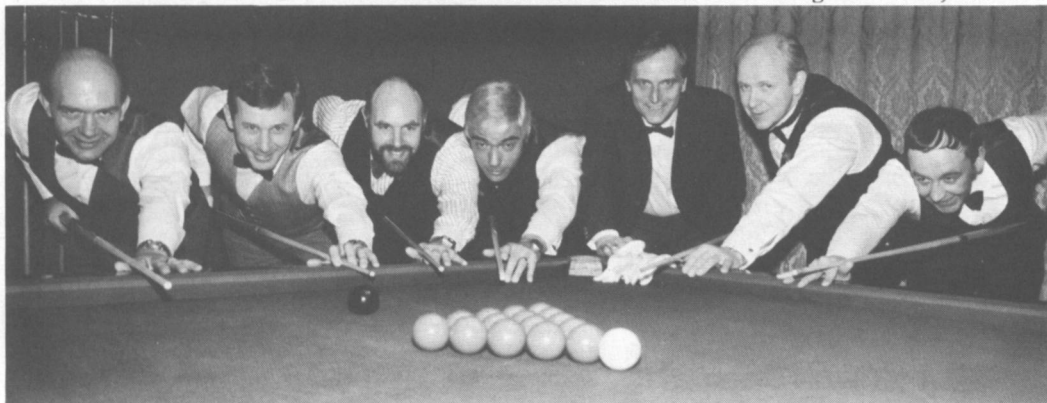
Thanks to their efforts and the generosity of people in the area it has made a profit of more than £4,000 in the first year.

There are 23 volunteers working on a part-time basis to help Mrs Gillmore — so the birthday cake had to be a large one!

ASBAH is very interested in looking for another shop in Mrs Gillmore's area — Gosport, Fareham — so if you know of any suitable premises, perhaps in an area scheduled for redevelopment where premises are inexpensive to rent, please do let ASBAH know.

Sussex

DAWN Coleman from Hastings in Sussex, who was featured in LINK Nov/Dec '84 when she was training to be a riding therapist at the Fortune Centre in the New Forest, has now successfully completed the course and this Easter started work at the Fortune as a fully fledged Assistant Groom.



Somerset

POT LUCK: Seven policemen — members of Avon and Somerset Police Traffic Department in Taunton — undertook a 24-hour snooker marathon in March. What happened to the traffic in Taunton we haven't heard, but financially the marathon was a great success raising more than £1,000 for spina bifida research, and cystic fibrosis research. Second from the right in the picture is George Earl, Chairman of Somerset ASBAH. The team completed 56 frames, and totalled over 4,900 points which may earn them a place in the Guinness Book of Records.

F. G. Construction

Building & Civil Engineering
Contractors

•

*Send Their Best wishes
to ASBAH for 1986/87*

•

**55 AUBREY ROAD
SHERWOOD
NOTTINGHAM**

Telephone:
Nottingham (0602) 608267

J. H. BOUNDS LTD

is pleased to support ASBAH
in its excellent work
and wishes it good luck

**68 Sackville Street
Manchester
M13 WJ
Tel: 061-236 7331**

MANUFACTURERS OF

- ★ **POLYTHENE BAGS**
(EX STOCK 24 HOUR DESPATCH OR
MANUFACTURED TO SPECIFICATION)
- ★ **REFUSE SACKS AND BIN LINERS**
- ★ **PALLET COVERS AND SHRINK GUNS**
(PLAIN OR SHRINK-FLAT, BOXED OR ON
THE REEL)
- ★ **SILAGE BAGS**
- ★ **BLOCK BOTTOM BAGS**
- ★ **CARRIER BAGS (PLAIN OR PRINTED)**

051-608 8046/7/8/9



**WESTAWAY
POLYTHENE LTD**
NORTH CHESHIRE
TRADING ESTATE
PRENTON, BIRKENHEAD
MERSEYSIDE

WISHING ASBAH EVERY SUCCESS

FLATMARA (Plant Hire) Ltd.

★ ★ ★

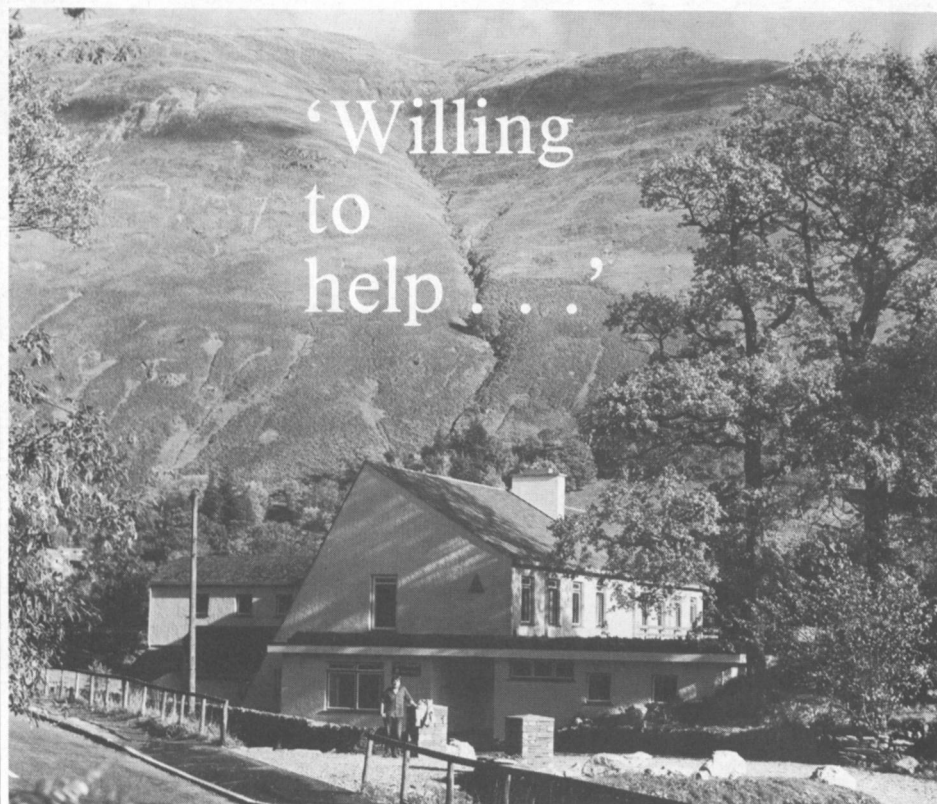
PLANT HIRE &
CIVIL ENGINEERING

★ ★ ★

WHITES CLOSE
(Off Wimsey Way)
**ALFRETON TRADING
ESTATE
DERBY DE5 7RB**

Telephone: 0773 608166

The Youth Hostels Association



Patterdale youth hostel in the Lake District.

ROPES, crampons and other climbing gear are a familiar sight at Pen-y-Pass youth hostel in North Wales and wheelchairs are often seen there too. The companionship of a hostelling holiday is not restricted to the able-bodied — and YHA is increasingly trying to welcome hostellers with mobility problems.

Pen-y-Pass, at the head of Llanberis Pass, is a former hotel. Hostel warden, Harvey Lloyd, and his assistants have made the hostel as convenient as possible for people in wheelchairs. They borrowed a wheelchair and tried it out around the hostel.

They designed and made ramps for steps and doorways, altered loo doors, and removed obvious obstructions.

The strong community spirit of the YHA was epitomised when volunteers from the local Bradford YHA group adapted Dacre Banks hostel — a former school — in North Yorkshire to cater for up to eight people in wheelchairs, and began the project by raising £500.

Most of the 260 youth hostels in England and Wales were originally built for other purposes: watermills, factories, schools, Elizabethan mansions and even a Norman castle have all been converted. Only a few hostels were purpose built, and among these is Broad Haven on the Pembrokeshire Coast which is the only hostel especially designed to cater for handicapped people. This single storey

building, opened in 1980, is in an ideal location for sea angling, boating and bird watching.

Another seaside hostel with ground floor facilities is Penmaenmawr on the North Wales coast, 10 miles from Colwyn Bay.

There are 50 hostels all around the country — wherever people like to go for holidays. Norwich is an example of a hostel in a cathedral city. It is a large house near the River Wensum on the outskirts of the city within easy reach of the Norfolk Broads for boating, windmills and birdwatching, as well as Norwich's 350 pubs!

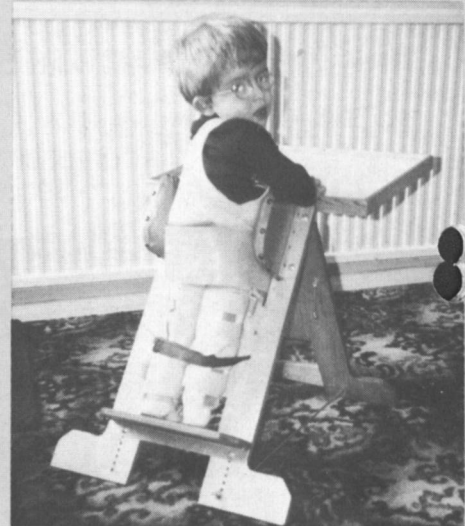
Pen-y-Pass, Dacre Banks, Penmaenmawr and Norwich are the only hostels in the 1986 YHA Guide with the wheelchair symbol. However, others have dormitories and toilets on the ground floor making them accessible to some people with mobility problems.

Finally, a comment from Dave Teare, the warden of Castleton hostel in Derbyshire Peak District: "I wish more disabled people would come here. Our facilities aren't perfect, but the staff are very willing to help."

Individual membership of YHA costs £5.50 (age 21 and over), £3.30 (16-20) or £1.10 (under 16) a year. Family membership costs only £11 (children under 16). Only the main leader of a group needs to be a YHA member. Hostels are graded. The majority are

How to make a 'Cloke' stand

Below are two views of a wooden stand built by Mr Arthur Cloke of Dover in Kent for his son Jason, 3, who has spina bifida and is paralysed from the waist down. The stand is about 22" high and folds up. Mr Cloke says it is very simple to make and inexpensive. It costs about £20. If anyone would like details of how to make the stand please contact Mr Cloke at 82 Coombe Valley Road, Dover, Kent, CT17 0EX. Tel: 0304 204895.



'standard' grade and carry a range of charges from £2.10 to £3.25, according to age. Most hostels provide inexpensive meals and almost all have a members' kitchen for self-catering. Some now offer a cafeteria or snack service.

The 1986 YHA Guide is free to members on joining, or may be obtained for £1.80 (postage included).

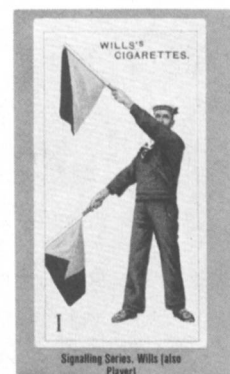
Also available is a free fact sheet for disabled people.

For more details, publications, or to join, the address is:— YHA, Trevelyan House, St Albans, Herts. AL1 2DY.



Anyone for Cartophily?

GERARD Starling, from Somerset ASBAH, explains why he has found Cartophily—cigarette card collecting—such a fascinating hobby. If other readers are interested in taking it up he will be happy to help. Why not write about your hobby for LINK if you think it's worth sharing with other readers?



CIGARETTES, producers of foul smoke, smelly breath, and a lot worse, gave one great benefit to mankind ... cigarette cards.

Now, as only the odd make of cigar issue cards, you need suffer pangs of conscience at collecting them by actually buying cigarettes. You must now look elsewhere for these 'small bits of cardboard'. But why should you even want to?

Unless the enquirer has had a hobby at sometime, particularly a 'collecting hobby', it can be hard to answer. How do you describe the enjoyment of hunting, sometimes for years, and then finding your quarry when

you least expect it? It's finding and possessing something that you wanted, of setting targets and trying to reach them.

A main attraction of collecting cigarette cards is the vast range of interests covered, and the number really is vast. Think of virtually any subject, and somewhere there will be a cigarette card to depict it from the common British frog to Errol Flynn, from the inside of a car engine, to Alice in Wonderland.

From this large range of choice you can pick a subject you want. In fact there are so many different areas, that you need a bit of self-control to select just one.

There are several ways of doing this, by limiting your collection to one make of card, for example John Player or Lambert and Butler, or to a certain subject, such as music or film stars. As an alternative, you can collect one card from a set to build up a 'type' selection.

A more practical reason for the attractiveness of cigarette card collecting is the cost. A set of fifty cards cost as little as £1.25, but can also range up to over £1000. Also, once bought, the cards retain their worth very well and can go up in value, so your money is not lost: though care must be taken in buying.

The major advantage for many LINK readers, however, is that you can collect from home, once a few addresses are obtained. Though there is a great deal of fun hunting in junk and antique shops, this can be equalled by searching through the regular (two a month at least) postal auctions with 200 to 400 lots a time. These are run by both large and small dealers. This way of collecting and selling cards has become very

popular over the last five years and is now the main method.

There are also monthly and two bi-monthly magazines providing articles, letters, news and adverts, which are a great help to any collector. One of these is run by the Cartophilic Society, the formal Association for Cigarette Card Collectors, who are always happy to help with information or advice.

The storage and display of cards used to be a problem. Now, relatively cheaply, you can store cards in clear plastic sheets, so that they are not damaged but are fully visible, both front and back.

There is much more I could say on this subject, but I won't here. If you are interested in cigarette card collecting please phone or write and I will supply addresses and any further information you may require to get started on this fascinating hobby.

Gerard Starling,
64 Maple Drive,
Burnham on Sea,
Somerset, TA8 1DH.
Tel: Burnham 786183.

OVALTINE

Why wait till
bedtime
to enjoy it?



T. S. ANNISON & SON

Funeral Directors — Private Chapels

QUALIFIED EMBALMERS

Would like to wish ASBAH every success for 1986

HULL (0482) 20278

122 Witham,

Hull HU9 1AT North Humberside

Street entertainers at the North Walk, Covent Garden.
Photo: British Tourist Authority.

'Oh, London is a fine town,
a very famous city,
Where all the streets are paved
with gold,
And all the maidens pretty'

George Colman

'OH, LONDON A FINE TOWN

Not everyone would agree with such comments about London, but it is a very interesting city, and nowadays a visit is not without difficulties if you are disabled, as has been in the past. Beverley Hollis, Information Officer, explains how to plan your visit.

LONDON is not only the capital of England, but is often regarded as the capital of Europe. Its mixture of ancient and new is often to be found side by side, like the 11th century Tower of London and the 20th century St Katherine's Dock complex. Whatever your interest you will find something here.

This article is not intended as a guide to what to see and where to go, but to tell you how to go about arranging your visit.

Where to stay is always a problem, as many hotels which are reasonably accessible are in the upper price bracket. One solution is the Tara Hotel in Kensington which has 10 rooms specially adapted to meet the requirements of people in wheelchairs or otherwise disabled. A concessionary rate is available to members of the Visitors Club (details below), membership of which is £1. The London Tourist Board also produces a list of hotel accommodation for disabled visitors.

Once you arrive in London there is the problem of how to get around. If you do not bring your own car one alternative is to hire one. Hertz Car Hire have some cars with hand controls for hire, but reservations should be made seven days in advance. Parking, however, is difficult and expensive, especially in the NCIP car parks. The Orange Badge is not valid in Westminster, Kensington and Chelsea, the City and South Camden, and cars which are parked illegally may find themselves wheelclamped!

A Helping Hand Across London is published by British Rail and is a guide to the most convenient Underground and bus routes between British Rail stations. Remember, however, that access to the Underground is usually by escalator or steps and therefore is not suitable for wheelchair users. If you can manage to get on a bus this is probably the best way to get around and see London. If you use a wheelchair then it is probably better to take a black taxi cab and most taxi drivers are co-operative and helpful and you can usually get one easily from your hotel.

Alternatively, you can hire a mini-cab, but do negotiate a price before starting your journey!

Once you have found your accommodation, worked out your transport, the question is where to go. There is so much to see and do. There are a number of very useful guidebooks on London for disabled people and a list is given below. *Children's London* is a good, reasonably priced, guide produced by the London Tourist Board. Not only does it give details of access, but suggests combinations of places to visit which are in easy reach of each other, for example a visit to the Museum of London can be combined with a visit to the Barbican and St Pauls Cathedral, or Madame Tussauds with the Planetarium, Regents Park and the Zoo.

Although parts of the Tower of London are now accessible, one of the major tourist attractions, the Crown Jewels, are not. However you can see replicas of these, together with those of 15 other countries, in the "Imperial

Collection" at Central Hall, Westminster.

A trip on the river can be combined with a visit to the impressive Thames Barrier and Visitors' Centre, with its working models and visual exhibition.

If you would like a more organised tour, rather than 'doing it yourself' you could hire your own personal guide. **William Forrester** who is himself disabled is a London Registered Guide and he will organise a tour geared to meet your needs. He also offers mini-bus tours around and out of London. This would be particularly useful for group visits where time is limited and you would like to see as much as possible. His charges are £37 for a half day, £55 for a full day tour. Minibus tours cost £170 for a day in London and £200 for a day out of London.

So you have seen all the sights and fed the pigeons in Trafalgar Square, it is probably time to find something to eat and perhaps visit the theatre or cinema.

The Restaurant Switchboard is available from 10 am to midnight and can offer suggestions on suitable accessible eating places. Do check, however, that the toilets are also accessible. All of the guides listed below also contain a list of accessible restaurants and pubs.

Artsline is an excellent information service which provides up-to-date access data on a wide range of entertainment venues and events. The Society of West End Theatres (SWET) publishes a fortnightly *London Theatre Guide* which

When a man is tired of London,
is tired of life;
there is in London
that life can afford'

Samuel Johnson

LONDON IS OWN'

such enthusiastic
a fascinating and
it is not a fraught
as it would have
alland, ASBAH's
plan your visit.

indicates venues with the best access and sound amplification systems. *City Limits* is a weekly guide to what's on and listings include access details. Theatre tickets can be expensive and very often a person in a wheelchair will have to sit in the most expensive seats, which can cost anything from £12-£20. However, there is a half price ticket booth run by SWET in Leicester Square where you can buy tickets for that evening's performance at some theatres.

The secret to a successful and enjoyable visit to London is to plan ahead and leave nothing to chance.

- 1 Make sure the railway station knows you are coming if you would like someone to meet you.
- 2 Make sure that the hotel is fully aware of all your requirements and is able to meet them.
- 3 Ring beforehand when visiting tourist attractions to make sure they are accessible, that you know which entrance to use and someone will be there to help you if necessary. During peak tourist times some places are not able to accommodate disabled visitors.
- 4 Book the restaurant in advance, let them know you are in a wheelchair, ask if there are any steps to negotiate and how high and make sure they are happy to have someone there in a wheelchair.
- 5 Book theatre and cinema tickets in advance, checking suitable accessibility.

One final word, why not call in and visit the ASBAH office? We are just south of Euston station!

One of London's most famous sights — the Houses of Parliament. Photo: British Tourist Authority.

**'Every drop of the Thames
is liquid 'istory'.**

John Burns.

USEFUL PUBLICATIONS AND ORGANISATIONS

Artsline Tel: 01-388 2227. A telephone information service for disabled people. Visitors Club. Membership £1 entitles you to concessionary stay at the Tara Hotel, Kensington. Details of membership from:— The Secretary, The Visitors Club, Juxon House, St Paul's Churchyard, London EC4. Tara Hotel, Kensington. 10 bedrooms suitably adapted for use by disabled people.

River Trips. Details from London Tourist Board special river information service Tel: 01-730 4812. To notify riverboat operators of your special requirements tel: 01-930 5947 or 01-930 4097.

London Tourist Board, 26 Grosvenor Gardens, Victoria, London SW1W 0DU. For tourist information tel: 01-730 3488. (Be prepared to wait for an answer!) The Board produces various publications and leaflets including a list of *Hotel Accommodation in London for Disabled Visitors* and a leaflet *Group Visits* which is a useful list of popular and lesser known attractions.

London Transport. London Transport Disabled Passengers Unit (Mr John Bull). Tel: 01-222 5600. It has been set up to look at ways of improving transport in the London area and to look at the possibility of providing accessible sightseeing double-deckers to do the very popular tourist routes. (It has also taken over the Dial-a-Ride Scheme and the Taxicard for London residents — from April 1.)

Hertz Car Hire. There are branches throughout London. Cavendish Car Tours Ltd, 441 Edgware Road, London W2, Tel: 01-723 6641.

Chelfont Line, 4 Medway Parade, Western Avenue, Perivale, Greenford, Middx, Tel: 01-998 2143 (coaches and mini-buses).

Kenning Car Hire, 478 Green Lanes, London N13, Tel: 01-882 3576.

William Forrester, 1 Belvedere Close, off Manor Road, Guildford, Surrey, GU2 6DP, Tel: 0483 575401 — personal guided tours.

Restaurant Switchboard, Tel: 01-444 0044, available daily 10.00 am to midnight.

SWET Ticket Booth, Leicester Square — open 2.30-6.30 pm.

GUIDEBOOKS

Childrens London price 60p, London Tourist Board.

London for the Disabled Visitor 95p, London Tourist Board.

HELP — Access Pack to London. Free from Thames Television, 149 Tottenham Court Road, London, W1P 9LL, Tel: 01-388 5199.

Access in London — Published by Nicholson's. Available from bookshops price £2.25.

Nicholson's London Restaurant Guide — £2 from bookshops.

A Helping Hand Across London. From British Rail Stations. Free.

Access to the Underground. A guide for the Elderly and Disabled. Available from London Transport, 55 Broadway, London SW1.

The Wheelchair Guide to London. Published by London Central YMCA, Great Russell Street, London, WC1. Free.

City Limits. From newsagents. *London Theatre Guide* from hotels and theatres — free.

BEST WISHES FROM: . . .

RIDGEWAY TYPE SERVICE

PHOTOSETTING AND I.B.M.
TYPESETTING

COMPLETE ARTWORK SERVICE

SUITE A, 12th FLOOR,
CITYGATE HOUSE, EASTERN AVENUE,
GANTS HILL, ILFORD, ESSEX
TEL: 01-554 7700

Rich Homes

D. A. & A. RICH



BUILDERS
COMPLETE DESIGN
& BUILD PACKAGE



*EXTENSIONS * ALTERATIONS
* REPAIRS * PRIVATE HOUSING
FINANCE ARRANGED WORK GUARANTEED
FOR PROFESSIONAL ADVICE & SERVICE RING:-

**RHUDDLAN (0745)
591253**

PENTRE LANE, RHUDDLAN, CLWYD

TURNER'S GARAGE

Howden Road, Barlby, Selby
SELBY (0757) 704356

Accident Repairs & Resprays
Any make of car or light commercial vehicle
Domestic & Trade — Enquiries Welcome
High Quality Work at Sensible Prices
Recommended repairers by most major
insurance companies



Established 15 Years

Wishing ASBAH every success

STEVE HILL GROUNDWORKS AND CIVIL ENGINEERING

Roads & Car Parks
Sewer Schemes
Bulk Excavation
Site Clearance

*Specialists in Laser
Pipe Laying & Infra Red
Beam Levelling Techniques*

Contractors to Local Authorities

Great Milton (08446) 8130

Hayesmoor Farm, Great Milton, Oxon

BEST WISHES FROM: . . .

ST. HELENS FABRICATION & MAINTENANCE LTD.

All Forms of Fabrications in
Stainless — Mild — Aluminium
Specialist Argon Welding

Tel: St. Helens (0744) 38964

UNIT 2
FLEET LANE INDUSTRIAL ESTATE
FLEET LANE, PARR
ST. HELENS WA9 9XX



PLUMBING & HEATING

37 HIGH ST., LINCOLN.

NEW INSTALLATIONS AND REPAIRS.
SPECIALISTS IN LEADWORK.

FOR PROMPT ATTENTION & EFFICIENT
SERVICE

Ring

Lincoln (0522) 42691

BEST WISHES FROM: . . .

RAMBLER HAULAGE

ROAD HAULAGE SERVICE
TO INDUSTRY AND COMMERCE

TO ALL PARTS OF THE U.K.

24 HOUR SERVICE

TEL: SANDIWAY (0606) 883081

CHESTER ROAD, OAKMERE
NEAR NORTHWICH CW8 9XX



Housing

by Siobhan Rowe

Published by ASBAH

THIS INFORMATIVE booklet was produced by Siobhan Rowe ASBAH's Accommodation and Development Officer before she left earlier this year. It aims to answer the kinds of questions that young people with spina bifida and hydrocephalus used to put to Siobhan — questions on how to find different types of accommodation, and how to pay for it.

It has been produced inexpensively by ASBAH 'in house' and is therefore being offered free of charge to parents and young people and 60p for professionals.

Available from The Accommodation and Development Officer, at ASBAH National Office.

Access in Paris

by Pauline Hephaistos Survey Projects.

Published by the London Communications and Mobility Cooperative.

THIS GUIDE was the major project of 1985 for Pauline Hephaistos Survey Projects, an independent investigative group who have produced a series of Access Guides during the last 15 years. It consists principally of boys and old boys from Hephaistos School near Reading and St Paul's School, Barnes and

includes both disabled and able bodied researchers, all of whom have wide experience of travelling and overcoming access problems.

The Guide is 112 pages packed full of general information, travel to Paris, travel in Paris, accommodation, sight-seeing, accessible loos, entertainments. It's wonderful value.

The group finances its work from sponsorship and voluntary contributions.

Price £2.75 plus 75p post and packing from: Pauline Hephaistos Survey Projects, 39 Bradley Gdns, W. Ealing, London W13 8HE.

REVIEW

Choosing Your Independent School 1985 - 1986 Edition

Editor: D. F. Woodhead
National Director, ISIS

THE INDEPENDENT Schools Information Service (ISIS) was started in 1967 to meet the demand from parents who wanted independent education for their children.

This book from the ISIS Director, aims to provide parents with details

Reading Matter

about recommended schools which belong to one of the constituent associations approved by the Independent Schools Joint Council, and to give parents the best advice about choosing a school.

It is a comprehensive guide to more than 1,350 Boarding and Day Schools for boys and girls aged 2-19 in the UK and Eire.

Probably, the most helpful chapter is the fourth, which provides a checklist of questions parents should ask when they visit a school. It is worth the investment of £3.50 by parents to guide them successfully through the complicated jungle of private education.

Denise Dunning,
Education, Training &

Employment Co-ordinator.

Available from: ISIS, 56 Buckingham Gate, London SW1E 6AG. Tel: 01-630 8795. Price £3.50.

Made-to-Measure Footwear and Orthopaedic Appliances

Take advantage of our expertise and discuss your individual requirements in the comfort of your own home.

With Poole's you can rely on almost 100 years of professional experience.

H.W. POOLE
AND SON LTD

HEAD OFFICE AND WORKS
CRISPIN HOUSE, NEW YORK ROAD,
LEEDS LS2 7PG

Telephone (0532) 433045

Also at
37 Parliament St., Harrogate.
Telephone (0423) 502939

86 Albion St., Leeds.
Telephone (0532) 433045

11-13 Micklegate, York.
Telephone (0904) 53208

2 Market Place, Driffield.
Telephone (0377) 42082



Let your Disabled Child ride a PONY

Unique, portable 3 wheeler (can be stowed in the boot of a car). Designed for the disabled child, but is fun for all children.

Here are a few super features:-

- Allows freedom and independence, indoors and out, enabling the child to move at a functional speed.
- Simple to operate and highly manoeuvrable, making it fun for the child.
- Compact and lightweight and strikingly attractive.
- 2 carefully proportioned sizes to cater for children from 4 upwards.
- Accessories available to meet child's needs.

PONY - The vehicle that lets children be children.

For a detailed colour brochure, fill in the coupon below.



Care Chair Division, ORTHO-KINETICS (UK) LIMITED
190 Commercial Road, Totton, Southampton. SO4 3ZZ

Name _____

Address _____

L86/5P

FIT & READY

With **SALTS** incontinence system

Salts Heritage incontinence system falls naturally into place whatever the circumstances may be. Unparalleled for reliability, ease of fitting and comfort for the user.

Salts Heritage incontinence system for the ultimate in comfort and convenience.

Heritage bags are opaque on one side and clear on the other, for ease of inspection. Non return valve and push pull drainage outlet are standard features. Simple adaptation for calf or thigh fittings, using one foam lined easily adjustable strap. If you are interested in the most up to the moment equipment from one of the foremost manufacturers in the field, take action now and make life easier.

SALTS Advisory Services

Are always here to help. Free from charge and without obligation.

- ★ Incontinence advisory service ★ Ostomy advisory service
- ★ Orthotic advisory service

If you require any information, or if you are in any difficulty concerning these subjects, please telephone or write to Salt and Son Ltd. 220 Corporation Street, Birmingham B4 6QR and re-assurance and help will rapidly follow from fully qualified experts.

If you would like to try Salts incontinence system please complete this coupon and post to:-
Salt & Son Ltd., Freepost, Birmingham B4 6 QR. You will then receive a Heritage starter with full instructions.

NAME _____

ADDRESS _____

LINK index issues 96-101 (1985)

Below is a list of the main articles which appeared in LINK during 1985. If you would like a copy of a particular article, or a back copy of LINK for last year, please get in touch with ASBAH's Information Officer Beverley Holland. She also has a complete list of LINK articles over the years.

SPINA BIFIDA AND HYDROCEPHALUS

SB and congenital hydrocephalus on the decline in Britain by Prof. J. Lorber. 98

MEDICAL AND GENERAL HEALTH CARE

Hydrocephalus in older children — problems are not easy to spot by Dr Pat Tomlinson. 96

The importance of regular valve checks. 96

Hydrocephalus — how parents and professionals can help by Leonie Holgate. 97

Hydrocephalus Support Group. 96, 98

Independence — parents can encourage independence of mind and body. 99

DISABLED LIVING

Comfortable seating for drivers. 96

Speedwell Supakart has good record. 98

Cheyne Scribbler. 98

One way brake. 98

Aquadry Penile Sheath. 99

Intermittent catheterisation. 100

HOUSING

VAT relief on house adaptations. 97

Short stay flat, Cwymbran. 97, 101

Housing and the right kind of help by Siobhan Rowe. 98

Newport housing scheme nears completion. 99

Carematch — computer find-a-home scheme. 99

Trafford and Salford housing scheme to go ahead. 101

A Home of Your Own by Siobhan Rowe. 101

WELFARE

Accident/illness insurance policies by J. Taylor (last of a series of financial articles). 96

Lost Babies Support Group formed. 99

Living Options (Report by Prince of Wales Group) by Siobhan Rowe. 99

Many don't have enough to live on by P. Thompson DIG. 100

ASBAH's views on Green Paper on Reform of Social Security by Beverley Holland. 101

It's a hard struggle for families in the North. Special LINK Report by Sue Gearing. 100

EDUCATION AND EMPLOYMENT

New MSC Code on Employment is first in Europe. 96

Sheltered Industrial Groups and ASBAH (Nina and Pamela). 97

Bristol Association's craft workshop. 97

Court Enterprises workshop (Birmingham). 98

Treloard College aims to give teenagers a key to a brighter future. 99

MSC offers money for pilot job schemes. 99

David works at potter's craft (Sheltered placement scheme — formerly SIGs). 101

LEISURE

Travelling abroad (helpful hints) activity and leisure holidays in Britain. 97

Expedition to the Sahara. 97

Canal boat holiday. 97

Swimming — the Halliwick Method by Margaret Reid Campion. 98

Jubilee Sailing Trust. 99

Holiday scheme for disabled children (Rainbow Club). 99

Sussex Association activity weekend by Bev Harries. 101

Proposals for cinema safety threaten rights of disabled. 101

INTERNATIONAL

Peace, participation and development in IYY by Paul Cooper. 96

My name is Marcel van Keelf by 19 year old from Holland. 97

Life has been kind to me by Cato Lie, 23, Norway. 99

Put on the Gloves of Self Esteem by Carolyn Jagger, Canada. 100

International Federation Conference in Manchester. 101

GENERAL

LINK's Special 100th issue. a special issue with a full colour cover to celebrate 100 LINKs



STEPHEN-CHARLES PAINTING LTD

DECORATING & PAINTING CONTRACTORS
UNIT V, PORTRACK WORKSHOPS
NORTH TEES INDUSTRIAL ESTATE
STOCKTON 606464



MOVE ON TRANSPORT LTD

- ★ NATIONWIDE DISTRIBUTION
- ★ LONDON DAILY
- ★ COURIER & EXPRESS SERVICES
- ★ EUROPE DIRECT
- ★ CONTRACT TRANSPORT

Estate Cars — Light Vans — 4 Ton Box Vans
Tail Lift & Flat Vehicles — 24 Hour Service

HENLEY (0491) 578131

UNIT 10, EMPSTEAD WORKS, HENLEY-ON-THAMES

BEST WISHES TO ASBAH FROM

SPOTLESS CLEANERS LTD



*WE'LL TAKE YOUR PREMISES TO THE
CLEANERS EVERY NIGHT*

INDUSTRIAL & OFFICE CLEANING SERVICES

THE COMPLETE SERVICE OFFERING:

UNIFORMED PERMANENT STAFF — SECURITY SCREENING — ON SITE
SUPERVISION — MODERN EQUIPMENT & MATERIALS — A SERVICE
TAILORED TO THE NEEDS OF THE INDIVIDUAL CLIENT — AT PRICES YOU
CAN AFFORD

147 JORDANSTOWN ROAD

WHITEABBEY 63328

WALTER LIST (HAULAGE CONTRACTORS) LTD

1 — 20 TON
ANYTIME — ANYWHERE

COMPETITIVE RATES

TELEPHONE: (091) 483 2020

11 PRINCE CONSORT ROAD
INDUSTRIAL ESTATE, HEBBURN
TYNE & WEAR, NE31 1BE

WISHING ASBAH EVERY SUCCESS
FOR 1986

THE OLD BAKEHOUSE LICENSED RESTAURANT

SPECIALISTS IN FRENCH
AND ITALIAN CUISINE

NOW OPEN LUNCHTIME
12.00 — 2.30

PARTIES WELCOME
AND FOR RESERVATIONS

TEL: SHREWSBURY (0743) 790482

BROOKSIDE, PONTESBURY
SHREWSBURY SY5 0QB

BEST WISHES FROM: . . .

ST. GEORGE'S NURSING HOME OF FERNDOWN

MED POST — OPERATIVE
GERIATRIC REGISTERED
NURSING HOME

FULLY TRAINED STAFF
DAY & NIGHT

TEL: FERNDOWN (0202) 872497

458 RINGWOOD ROAD, FERNDOWN, DORSET
BH22 9AY

BEST WISHES FROM: . . .

MIDDLEWHAY MARINE LTD

NEW AND USED GENERATORS FOR SALE OR HIRE
ALL SETS AVAILABLE FOR HIRE OR FOR SALE
ALL CARRY FULL WARRANTY
FULL RANGE OF GENERATING SETS FROM 5-1000 KVA

FOR FURTHER DETAILS RING OR WRITE

THE CROSS, RINGER LANE, CLOWNE, CHESTERFIELD,
DERBYSHIRE

TEL: 0246-819577

BEST WISHES TO ASBAH FROM

FERROFLUIDICS

High Tech Sales

Floor 7,
Seacourt Tower
Botley, Oxford
OX2 0JP

● A Code of Practice on Arts and Disability has been published by the Arts Council, the Scottish and Welsh Arts Councils and the Arts Council of N. Ireland.

Each has urged its clients to adopt the Code of Practice which covers liaising with disability groups, ensuring disabled people are given more employment opportunities in the arts, ticket-pricing policies, information and publicity, improving physical access to premises and changing attitudes towards people with disabilities. The Arts Council have called on all their revenue clients to implement the Code of Practice within

the next two and a quarter years and have agreed to monitor its implementation. The Code of Practice is one of eighteen documents which are contained in the Arts and Disability Resource Pack: £5.00 inclusive of p and p, from: Arts Council, 105 Piccadilly, London W1V 0AU.

● LINK readers will be delighted to hear that Prof R W Smithells of the Department of Paediatrics and Child Health at the University of Leeds has been presented with the Harding Award for his work into the possible prevention of neural tube defects by vitamin supplementation. The award is given in memory of Field-marshal Lord Harding.

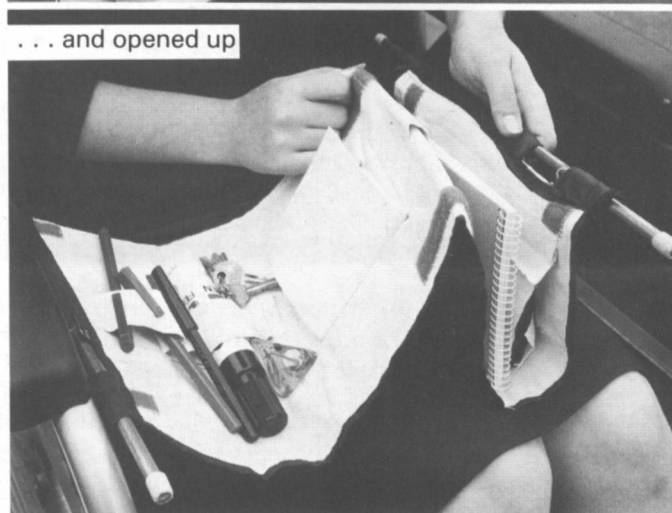
● Sun Alliance has introduced a Special Aids Scheme for Disabled People to insure their communication aids, microcomputers, typewriters and other special equipment against 'All Risks'. They say that in the past it has often proved difficult or expensive for people with disabilities to obtain adequate insurance cover on this type of equipment. The average premium is likely to be between £20 and £25 according to the value and type of equipment being insured.

For details contact Sun Alliance at Rickford House, 12 Rickford Hill, Aylesbury, Bucks, HP20 2RZ. Tel: 0296 24688.

Newslines NEWSLINES Newslines



The bag folded . . .



. . . and opened up

● Gloucestershire Association for the Disabled has a holiday caravan to hire in the Forest of Dean. The 26 foot caravan has been specially adapted, and would sleep four. Mains services. It is situated in the grounds of Dean Hall School, close to the Speech House Hotel. Available at weekends, half term and school holidays. Details: Margaret Thompson, Warfield Farm, Ruardean, Gloucs. phone Jan Lyden: 094 23231.

● Polka Children's Theatre in south-west London welcomes disabled children and is wheelchair accessible. It has a full programme of plays for this year and also holds puppet workshops especially for disabled children (at a cost of only 25p per child). For a

Photos: Design Council theatre programme contact: 01-543 4888, and for information about the workshop contact: Maomi Adler, Tel: 01-543 0363 or write to her c/o The Polka Children's Theatre, 240 The Broadway, London SW19 1SB.

● SALVO — an experienced clown who had to give up his career as a result of a road accident now travels round the country giving charity shows at fetes, bazaars, carnivals etc. He can put on an hour's show which includes balloon modelling. All he asks is for his expenses and the balloons to be provided. If you would like to know more about Salvo contact him (sae please) at 13 Second Avenue, Hart Road Caravan Park, Thundersley, Essex.

Fold-a-bag wins prize

THIS FOLD-A-BAG for wheelchairs has won the designers, 14 year old Georgina Williams and Clare Spencer of Monmouth Comprehensive school, Gwent, a prize in the 1985 annual Schools Design Competition.

An accident which resulted in Georgina's mother having to use a wheelchair started the two girls wondering how to make life easier for people like her.

When Georgina and Clare visited a local home for the disabled, they found people in wheelchairs using either bags hanging on the pushing handles behind them, which were impossible to reach, or holding a heavy, cumbersome bag on their knees.

Their solution, the 'Fold-a-bag', clips neatly to the underside of the arm rest and can be opened, concertina-style, across the user's lap and clipped to the other side, leaving both hands free. Opened up, the bag has a variety of pockets and loops to hold, for example, money, writing pad, keys, pens and a spectacle case. Stiffened central sections make a fairly rigid surface. Folded the bag measures 24cm x 17cm with 35cm alloy rods at the top. It is made of nylon and lined with calico.

The judges felt the project had been carried out in an enthusiastic and efficient way, resulting in a useful product.

The competition was organised by the Design Council and sponsored by Thorn EMI.

The cost of the bag and hooking on clips (for the opposite chair arm) is £6 plus £1.50 post and packaging. Cheques should be made payable to 'Monmouth Comprehensive Enterprises'.

Available from: MINNOW Enterprises, Monmouth Comprehensive School, Old Dixton Road, Monmouth, Gwent NP5 3DP.

BEST WISHES FROM

CRAVEN SCAFFOLDING

SCAFFOLDING SPECIALIST

**SUPPLIERS TO DOMESTIC
& INDUSTRIAL**

ALL TYPES OF CONTRACTS UNDERTAKEN

- ★ SUB CONTRACTING
- ★ LABOUR ONLY
- ★ HIRE ★ SALE
- ★ SUPPLY & ERECTION

061-969 1372

061-973 9403 (EVENINGS)

237 CROSS STREET, SALE,
CHESHIRE M33 1JR

Wishing ASBAH every success

LECRAFERN LIMITED **Civil Engineers**

Excavation, Site Clearance, Demolition & Tarmacing

Security Fencing Specialists

Also Machinery Hire

Tel: Shorne (047482) 2786

2 EASTCOURT COTTAGES
LOWER HIGHAM ROAD
CHALK
NR. GRAVESEND
KENT

A. GIBSON **ROOFING CONTRACTOR**

ALL TYPES OF DOMESTIC & COMMERCIAL
WORK UNDERTAKEN

- ★ ALL TYPES OF ROOFING
- ★ GUTTERING
- ★ CHIMNEYS RE-POINTED
- ★ GENERAL PROPERTY REPAIRS
- ★ PERSONAL MAINTENANCE SERVICE
- ★ COMPETITIVE PRICES
- ★ FREE ESTIMATES

STOKE-ON-TRENT (0782)
810675

BUSINESS ADDRESS
73 BOND ST., TUNSTALL, STOKE-ON-TRENT

K JOWITT & CO **BUILDERS AND PLASTERERS**

EXTENSIONS — CONVERSIONS —
ALTERATIONS — ROOFING AND
GUTTERING — REPLACEMENT WINDOWS
JOINERY — PLUMBING AND ELECTRICAL
WORK UNDERTAKEN . . .

19 JENNINGS CLOSE, SILSDEN,
NR. KEIGHLEY, W. YORKS BD20 0QN

STEETON (0535)
55094



PEMBROKE **THERMAL INSULATION**

THERMAL INSULATION ENGINEERS
SHEET METAL FABRICATORS
REFRACTORY LININGS

Unit 17, Waterloo Ind. Est., Pembroke Dock
SA72 4RR. Tel. (0646) 682500

Wishing ASBAH every success

WHIDDON VALLEY ENGINEERING LTD

Precision Engineers

Toolmakers of Lost Wax dies,
Jigs and Fixtures.

Turn Parts production machines

Also fabrication of specialist
built machines.

Tel: Barnstaple (0271) 76288

Units 1 & 5
Whiddon Valley Industrial Estate
Barnstaple
Devon

BEST WISHES TO ASBAH
FROM: . . .

HAWKINS BROS.

DENNY END INDUSTRIAL ESTATE
WATERBEACH
CAMBRIDGE

TEL: 0223-861499

STRUCTURAL STEEL ERECTORS
AND
CLADDING CONTRACTORS

DAVID VAUGHAN **& CO LTD**

BUILDING CONTRACTORS

- ★ CONTRACTORS TO LOCAL AUTHORITIES
- ★ COMMERCIAL & INDUSTRIAL REPAIRS & MAINTENANCE
- ★ ALTERATIONS & MODERNISATION WORK
 - ★ HOUSE BUILDERS
- ★ DESIGN SERVICE AVAILABLE

TELFORD
(0952) 57875

ROADWAYS HOUSE, HOLYHEAD ROAD,
KETLEY, TELFORD, SHROPSHIRE



When mothers learn their unborn child is abnormal — that's the time for a special kind of support

WHEN I WAS appointed to the position of Sister-in-Charge of the ultra sound unit at King's College Hospital it became quickly obvious that there should also be an emotional support and counselling service available for mothers who were told by the diagnostic team that their babies were abnormal. Having done some research myself and found that there was no such organisation I decided to start a support system for patients referred to King's College in an attempt to help these parents understand and cope with their feelings during such a traumatic experience.

SARA KENYON
King's College
Hospital

I GOT permission from Professor Campbell, Head of Department and contacted all consultants nationwide, from the Orkneys to Cornwall, who refer patients to the obstetric ultrasound Department at King's College Hospital requesting their permission to write to their patients following their visit to us. Of the 95 hospitals and 302 consultants, 40 said they thought this would not be necessary.

Starting on November 1, 1984 all parents who were found, by the ultrasound team, to have abnormal babies were contacted. Two weeks after the ultrasound diagnosis I wrote to each one explaining that we were setting up a counselling service to help mothers who had been through such a traumatic experience, and saying I was available for counselling if they needed help.

In the six months from then, 733 patients, considered to be particularly at risk of an abnormal fetus, have been seen for a high resolution ultrasound scan. During this period some 80 abnormalities were detected and were felt by the team to be serious. Due to obvious constraints it was decided that I could not offer a home visit and would only counsel those mothers who contacted me and requested further emotional support counselling.

It is the policy of the unit, with the blessing of the referring consultants, to describe as exactly as possible the seriousness of the babies abnormalities and the long term prognosis for the child. The immediacy of this diagnostic information is one of the great advantages of ultrasound. All the patients seen in these situations are obviously highly stressed and worried and have usually had to wait for an appointment to be scanned at King's College Hospital.

The delay in obtaining an appointment is unfortunately related to the huge demands on our services and also depends on the background information given by the referring hospital. If a clear referral with all details of highly suspicious findings is given these patients are seen within two days. If the referral is less concise or if the risk of abnormality appears low a longer delay may result. The reasons for referral clearly vary greatly and it has not always

Struggling with grief following termination of pregnancy

been explained to parents why a scan at King's College is considered necessary.

During this six month period I saw some 25% of parents in whom we detected serious fetal abnormality. We felt the numbers of parents who responded to our invitations encouraging, considering that some parents do not require external counselling and that some will associate us with the bad news and may not return for that reason. In addition the travelling distances involved for parents may be considered too time consuming and expensive.

The couples were interviewed at about a month after their initial visit to us and further offers of interviews were accepted in 80% of cases. These were all offered for a month later but were usually brought forward by the couples themselves.

Findings

Many of the women that we counselled said that they were told very little by their own doctors and yet they instinctively knew something was not right. While understanding the reasons of their doctors for not alarming them unnecessarily the parents felt it could have been more helpful and less worrying to have had more information as to the reason for their referral.

The parents stated that if they had had more frank discussions with the doctors at their referring hospital they would have possibly been able to absorb the bad news easier. Even in those cases where explanations were made to parents they felt numb and only heard a certain proportion of what was told to them. This points to the needs for repetition and repeated explanation when coun-

selling at these times. Following the scan a description of abnormalities is given to the parents in as non-directive way as possible.

The parents are then referred back to their local hospitals to be seen by their consultants, usually within a day, and a decision is taken as to whether to continue or terminate the pregnancy. The couples I saw felt that the decision reached was their own and the right one but also, to some extent, felt prisoners in an inexorable chain of events.

Most of the couples opted to terminate the pregnancy based on the ultrasound findings, but a small number, for various reasons, decided to continue despite the knowledge that the fetus would probably not survive, and that if it did, it would be mentally and/or physically handicapped. All said what a very difficult decision this was to make, because these babies were all wanted and loved.

All the women found the termination itself, being an induced mini labour, far worse and more painful than they had anticipated and have stated that they would have liked more information about what it involved beforehand. They had, on the whole, found the doctor's, midwives and nurses who cared for them supportive, helpful and sympathetic. The few that had not, felt that it was the professional person's inability to cope with their own feelings rather than for any other reason.

The reactions of the parents to the termination were naturally profound and they used words such as *shattered*, *bewildered*, *angry* to describe their main emotional responses. The majority were not offered either genetic counselling for the abnormality detected or emotional support and counselling to help them cope with their loss. Some were referred

*This article first appeared
in Nursing Mirror*

Continued over Page

Continued from Page 25

to either the Miscarriage Association or S.A.N.D.S. (Still birth and Neonatal Death Society) but felt these organisations were not appropriate to their needs.

All appeared to experience the normal emotions associated with the aftermath of the termination i.e., sadness, anger, shame and disbelief. The overwhelming emotion when they first arrived home was a feeling of isolation and sadness and a feeling that this hadn't happened to anyone else.

A large proportion felt guilty about what they had done. Although common sense told them the decision they had taken was the right one they still wanted the baby and regretted that the pregnancy had been terminated. Some parents felt that it had never happened and that it had all been a nightmare. Some of the mothers felt that even strangers would know what they had done and for this reason avoided going out. They found that their anger was the hardest emotion to understand and cope with as there was usually no one and nothing to which and to whom blame could be attached and directed. They blamed themselves to some degree although they knew this was misplaced.

All these feelings are part of the grief process but they are made harder by the fact that there is nothing substantial to grieve for. Most parents saw their babies after delivery and found this was very important for two main reasons:

- Firstly, they found the baby appeared normal except for the particular abnormality and found immense reassurance to know that their baby was not a hideous monster.

- Secondly, they found it important as they then had something to grieve for and a memory of someone.

All said that they were apprehensive about seeing their babies but all were glad that they had done so. The few who did not see their babies merely said that they did not want to do so with one exception who explained that she knew the baby would look normal and thought she would find the decision to terminate the pregnancy even harder to come to terms with. Those who had been given photographs found them very helpful.

At the time of the termination many women felt that arranging for the burial of the baby would have been too much to cope with, but this was something that they regretted afterwards and many of them asked what happened to the babies bodies. One of the women had buried her baby and found once she had done that she felt at peace.

Religion played an important role in determining the degree of guilt felt by some parents. Those who had either at

Struggling with grief . . .

present or in the past had a strong faith found they felt as if they had sinned deeply. A couple of them had been to the local priest who had been helpful and supportive.

It varied how the couples coped with these feelings and to whom they turned for support, but one common finding was that they received most support from each other, particularly if the partner had been present throughout. Where the potential problems arose was where the couples relationship was already experiencing difficulties without the added stress of the termination of an abnormal pregnancy.

The experience was something that most couples found difficult to talk about to other than those they were close to. Some of the women remained indoors longer than necessary following the termination because they did not wish to meet someone that they knew and to whom they would have to explain what had happened. They could not do this without tears in the beginning but gradually it became easier.

All the couples said that it would have been helpful to see another woman who had had the same experience when they came out of hospital and that they would be willing in the future to attempt to help someone else.

Many of the women expressed a feeling of being unsuccessful in motherhood. No matter whether the woman has been working or not, her maternal instincts take over when she is pregnant. When the pregnancy ends in such a traumatic way with no end product the mother is left with a feeling of failure and being unable to fulfil her function. In those women who had other normal healthy children, this feeling was not as overwhelming. Some of the women who had no children also said that they found themselves becoming obsessional housekeepers in an attempt to cover-up this feeling of inadequacy.

Conclusions

These results suggest that the response to a late termination of a wanted pregnancy as a consequence of advances in prenatal diagnostic techniques is often an acute grief reaction, similar to that experienced after stillbirth and akin to that after any death. It is a normal

process which may require professional help.

We felt that the severity of the reactions may have been because mourning was in general, difficult — there is no grave, no baby, and usually no photograph. The “death” was passed over, thought of “merely” as a miscarriage by most people. This should not be so. A miscarriage is, after all, an act of God and choosing to terminate an “unwanted” pregnancy must be very different from ending a wanted pregnancy, as in this instance.

This study has exposed a very large gap in our present maternity services as a whole and confirms the work of J Lloyd and K M Lawrence(1). This work is only the beginning of what should be an expanding role for midwives in pregnancy counselling whether the pregnancy is successful or not.

REFERENCES

(1) Sequence and Support after termination of pregnancy for fetal abnormality. Lloyd J, Laurence K M, British Medical Journal Vol 290 Pages 907 – 909.

ACKNOWLEDGEMENTS

Professor Stuart Campbell, Head of Obstetrics and Gynaecology, King's College Hospital.

Mrs C V Smither, Director Midwifery Series, King's College Hospital.

Myra Hunter, Clinical Psychologist, King's College Hospital.

All the couples I have seen.

Support Group formed.

SATFA (Support After Termination for Fetal Abnormality) was set up the instigation of ASBAH about a year ago as the result of the obvious need of parents like those mentioned in Sara Kenyon's article above.

The aim is to offer help to parents who are facing a termination or who have just experienced it and need someone to turn to. At present counselling is being given voluntarily by two experienced professionals, but the aim is to set up a mutual support network of parents.

Those facing termination will be put in touch with others who have themselves lost a baby in the same way.

The SATFA Steering Committee has been set up made up of voluntary organisations, professional people, nurses involved with counselling.

If you would like more information contact SATFA, c/o ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01 – 388 1382.

MEETING POINTS

WHEELCHAIR CHALLENGE DAY

**ASBAH National Office,
22 Upper Woburn Place,
London WC1H 0EP
June 8**

Following the success of a wheelchair mobility session at the recent LIFT weekend, ASBAH has decided to hold something similar at national office in June.

Owen McGee and Pat Owen from the Elizabeth Fry School in London, who conducted the LIFT session, will be in charge again, with the help of LIFT.

The idea is to give anyone who uses a wheelchair the chance to practise new skills — to tackle ramps, kerbs, and all kinds of obstacles that you may never have thought possible in a chair.

The group will visit other London venues during the day to show how mobile you can be.

The day is free. If you'd like to know more contact the LIFT office at National. It should be a very challenging day.

ASBAH SEMINAR

For older people with spina bifida and hydrocephalus (pre 1956), and carers.

**ASBAH National Office,
Friday, June 13.**

Further details of this first ever seminar of its kind will be available later. If you would like a programme and information contact Miss Beverley Holland, Information Officer at National Office.

1986 ASBAH CONFERENCE

**Sorby Hall, University of Sheffield.
September 5-7**

ASBAH'S STRUCTURE

Since the announcement about the Conference in the last LINK it has, as a direct result of the discussions at the last Council Meeting, been decided, to change the programme. It will now concentrate on the future structure of ASBAH.

It will be a chance for local and national members to meet together and talk about the nature and structure of ASBAH at all levels. As a result there will only be a little time for outside professional speakers.

It should be a wonderful opportunity for a big get together and in order to encourage as many people as possible to



Over 60 young people with spina bifida and hydrocephalus met together in Manchester for the third LIFT weekend.

They kept themselves very busy with discussions, workshop sessions and social gatherings, and by all accounts a good time was had by all.

It certainly seems so from the photo which focuses on two members, John McGovern and Mary King.

come the price is being reduced to a minimum of £40 per person.

If you haven't received details through your local association, contact Mrs Susie Dobson at National Office as soon as possible.

House exchange

Home from Home

WHY NOT exchange your house for the holidays? LINK reader, Mrs Karin Craig of Margate in Kent has a 3 bedroomed house which she would be willing to exchange for similar accommodation anywhere in Britain for a holiday this year.

Mrs Craig has 4 year old twins. She is herself disabled and the house is, therefore, very suitable for someone in a wheelchair. There is a patio, lift and shower, and of course Margate is a very popular holiday spot.

If anyone would like to contact her the address is: 10 Friends Avenue, Margate, Kent. Tel: 0843 296712.

● LINK would be pleased to hear from any other readers who might be willing to swap houses for a holiday either with a family in this country — or abroad.

Why not let us know.

FFESTINIOG SLATE CO. LTD.

**OAKLEY QUARRY
BLAENAU
FFESTINIOG
GWYNEDD**

**MANUFACTURERS
OF FFEISTINIOG BLUE
GREY ROOFING
SLATES, SLATE
SLABS & BUILDING
STONE, FLOOR
TILES, NATURAL
AND COLOURED
CRAZY PAVING.**

**FIREPLACES MADE
TO ORDER.**

**TELEPHONE:
0766-830204.**

Wishing ASBAH
every success
throughout
1986

Clarke Excavation Ltd

Civil Engineers

**43 CANNING STREET
LIVERPOOL
L8 7NN**

051-709 4673

Some thoughts on living with disability from two people from different sides of the world.

'It really isn't so terrible'

Cynthia Cuchna,
A 20 year old student at
Edinboro University of
Pennsylvania, USA.



This article is reprinted with permission of INSIGHTS, the magazine of the Spina Bifida Association of America.

MOST people would say, "It would be terrible to be born with a birth defect." "Well, I know firsthand that it really isn't so terrible. I have been blessed with family and friends who have not let me feel that my disability should get in the way of reaching my goals.

My parents have never let me use my handicap as a way of getting out of responsibilities. I have the same

the high school I had to attend, which is outside my local school district and is the only school in the country capable in handling my special problems. We can't

Personally Speaking...

responsibilities around the house as my sisters and if I don't take care of them I am equally disciplined just as my sisters would be if they didn't do their share of the work. I feel my oldest sister, Sherri, has helped me the most in believing that I am just as capable as anyone else in doing things for myself. If I would ask her to get me a book or a glass of water, Sherri would probably say something like, "Get it yourself, you aren't helpless!" I wouldn't want it any other way between us.

People have asked me if I feel my sisters are allowed to go more places and do more things than me. I don't feel that I've missed out on any of the experiences my sisters have had. I go to football games, movies, go shopping and go to the local disco just like them.

The only problem I have is that most of my friends live too far away for me to just "drop by" whenever they feel like it. My friends are my classmates from

even call one another very often because it is long distance.

Hospitals have been a very important part of my life, since I was in and out of them quite frequently when I was young. I never really minded going into the hospital because the doctors and nurses were always nice and I knew they would take good care of me.

Along with hospitals came bills. Our family had never been eligible for financial aid because my parents always made "too much money." I know at times it has been tough on my parents to make ends meet because I am such an "expensive kid." Sometimes I feel guilty about having my parents pay such big bills just because of me.

I have been in braces ever since I was four years old. I know that they have helped me considerably, but often I have negative feelings about my braces.

There was a time when I was unable to wear my braces due to pressure sores. I liked being out of them because my clothes weren't torn by the locks on my braces and I liked getting dressed faster.

I thought I looked prettier without all of that plastic and metal sticking out of my clothes.

I am finally starting to realize that I look better in them because they make me straighter. I don't look like I'm a 'pretzel' when I'm in them, which enables me to do things and go places that I couldn't in my wheelchair. Even though the negative feelings may resurface in the future, I plan wearing them a lot more than I have the past two years.

When I go out to a movie or shopping, sometimes people stare at me. This has never really bothered me. It just shows me that they are interested in my disability and are curious to see how my braces, crutches and wheelchair work.

I especially like it when little children come up to me and ask, "What happened to you?" I am glad that children aren't afraid to ask questions. I wish that adults would open up and ask, because I would be more than willing to tell them about anything they would want to know.

My plans for the future are to graduate from college with a degree in psychology. I think that I would like to be a school psychologist because I love children. I know that the road ahead will have some rough spots, but I know that I can make it with the love and support of my family behind me.

'Trying to prove something'

John Henry Hughes,
An actor from
Cambridge.

WE spina bifida sufferers are an awkward bunch of so and so's aren't we?. Have you noticed that if there is a 0.1% chance that we can do something we shun all offers of help. May we NEVER change.

Seriously, we do seem to spend an awful lot of time trying to prove something. In my case my wife and children keep saying "Stop trying to be super-human; people will accept you for what you are, not what you think you'd like to be". When I was younger I did all the stupid things that 'normal' people wouldn't even consider. For example my sports were — motor racing, gliding, cricket and, wait for it, judo. It never stops. Now at 46 I am an actor and, while directors and other actors do all that they can to make life easier for me, I mess everyone up by doing it my own way anyway.

The other thing is that we are exceptionally happy people. I have yet to meet someone with SB who doesn't have a sense of humour. To those of you

who want to show off that sense of humour get involved in amateur theatre. I say theatre because there is always so much to do for each and every one of us, both front and backstage, and believe me you quite often need a better sense of humour off stage than you do on stage. The other nice thing about theatre is that we are in a position to encourage people to laugh *with* us rather than laughing *at* us because, inevitably, we are conscious of our disability and we shudder to think that people may be making fun of us. Perhaps that's why we have to keep proving.

How many of us, on admission to hospital, has waited until the houseman has put away all his kit and then told him that he's forgotten to do reflexes, eyes or a dozen or so other things. I only wish that, once in a while, they would accept that we do know almost as much about SB as they do and that, in certain cases, we are something of a novelty to them.

Having lived with it all my life I can cope but I must admit that the day,



recently, that my seventeen year old daughter Sian came back from the doctor and told me that he thought that she might have spina bifida occulta it really shredded my emotions.

It turned out to be a slipped disc which, while serious enough in itself, beats the hell out of having SB. I think too that in that moment I felt perhaps a small part of what our parent's must have felt since our birth, a profound sense of guilt at having brought into this world a less than perfect human being. However misplaced that feeling may be it nevertheless exists and maybe it is in this area that we can show off our very best quality — the ability to show love and the ability to share it.

ASBAH News

Fit for work

ASBAH was awarded a Certificate of Merit in the 1985 MSC Fit for Work Award Scheme in recognition of its achievement in employing disabled people.

Farewell to Siobhan

Many people will be sorry to hear that Siobhan Rowe, ASBAH's Accommodation and Development Officer has left after 2½ years in order "to broaden her horizons". She has gone to the Housing Advice Switchboard — a housing advice service for single homeless people and childless couples covering the London area. Siobhan was a very caring and dedicated member of staff, and wrote a number of excellent articles in LINK.

Welcome to Carolyn

The new Accommodation Officer (from June 9) will be Miss Carolyn Smith. She has a Sociology degree, and has worked with disabled people in Lambeth, London, researching housing and planning policies.

The marriage of Lord Maybray-King

ASBAH was pleased to send its very best wishes to the Rt Hon Lord Maybray-King, President of the Executive Committee on the occasion of his wedding to Miss Sheila Atkinson on March 29 at Bitterne, Southampton.

LIFT goes to Holland

LIFT is organising a trip to Holland, July 12-19 staying in an accessible holiday centre in a wooded area in the East, close to the German boarder. The venue is Werkenrode which during term time is a residential educational centre for physically handicapped young people, and doubles up as a holiday centre.

The week's holiday will include sight-seeing to places such as Amsterdam, museums, mills, farms, a Zoo and Safari park, and trips on the Rhine.

LIFT is making up a party of 35 members. For details contact, as soon as possible: Andrew Neale, LIFT, at ASBAH National Office.

OBITUARY

Kate White

Kate White joined ASBAH in 1971 to run the Appeals Department. She quickly proved her sound business sense and professional skill.

The demands made on an Appeals Organiser are onerous and diverse. Kate accepted every challenge cheerfully whether racing pigeons, inflating 100 balloons in the pouring rain or selling hundreds of ball tickets. To have helped treble the income coming to the Association has been an important contribution to ASBAH's needs: to have arrived when there was no fund for a Research Fellow nor any Residential Centre and to leave with Mr Bayston in post and Five Oaks in operation should have afforded Kate much satisfaction.

She brought great dedication to her work but more importantly great humanity and capability.

A memorial service was held in Aylesbury on April 26, at which ASBAH was represented by the Chairman Mr R. R. Mackenzie, accompanied by Lady Jean. Miss Moyna Gilbertson, Frank Armour, Miss Mary Oughtred and Mr H. D. Macfarlane were also present.

TSW PRINTERS

**LETTERPRESS, LITHO AND
THERMOGRAPHIC PRINTERS**

- ★ Photocopying
- ★ Business Stationery
- ★ N.C.R. Invoice Sets
- ★ Leaflets & Posters
- ★ Duplicate Books
- ★ Specialists in Draw, Tote and Raffle Tickets
- ★ Your Local Supplier of Bingo Tickets

FOR A FAST AND RELIABLE SERVICE

PHONE

SCUNTHORPE 861655

236 FRODINGHAM ROAD, SCUNTHORPE

NIBS INC.



DESIGN, TYPESETTING & GRAPHIC ART

Nibs Inc. offers you the whole range of services one would expect from a graphic art studio. We are pleased to work to your brief or turn your ideas into visual conceptions and follow these through to typesetting, illustration, finished artwork and printing.

We can also offer the not-so-usual requirements such as cartoons, technical illustrations and one-off cards.

Ring Steve or Sue on (0296) 35310

Chiltern House, Oxford Road, Aylesbury, Buckinghamshire HP19 3EQ

CampbellC

**COMMERCIAL, INDUSTRIAL AND
RESIDENTIAL CONTRACTORS
ALSO**

**COMPLETE DESIGN AND BUILD
AND PACKAGE DEAL SERVICE**

BRISTOL (0272) 736835

**MARK MOOR (027864) 430
EVENINGS**

8-10 WHITE LADIES ROAD, BRISTOL

WRIGHT WINDOW SYSTEMS

**"A GOOD NAME TO HAVE
IN YOUR HOME"**

FOR REPLACEMENT WINDOWS AND
DOORS

NICE PEOPLE TO DEAL WITH

LINCOLN 21011



PARK STREET, LINCOLN

M. FRAZER COOK LTD



- ★ BUILDERS
AND
DECORATORS
- ★ EXTENSIONS
AND
CONVERSIONS
- ★ DOMESTIC
AND
COMMERCIAL

24 HR TELEPHONE ANSWER SERVICE

**TITCHFIELD
(0329) 43176**

ALPINE GARDEN CRAFTS

LARGE RANGE OF:-

- ★ PATIO SLABS & WALLING
- ★ SAND BALLAST & CEMENT
- ★ SHEDS
- ★ GARDEN FURNITURE
- ★ RUSTIC FURNITURE & POLES
- ★ ARCHES, ETC.

FIND US AT:

HIGH HOUSE GARDEN CENTRE
CORBETS TEY ROAD
UPMINSTER, ESSEX

UPMINSTER (04022) 25800

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rate: £2.50 for 30 words max; £3.75 for 30-45 words; £5 for 45-60 words. Cheque or postal order payable to 'ASBAH'.

Adverts for next LINK (July/August) should be in by June 5. Send to: The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington. Avon, BS18 7NE. Tel: 0934 862279.

HOLIDAY ACCOMMODATION

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.

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.

PRIMROSE VALLEY. Fully adapted luxury caravan, sleeps 6. Shower, toilets, ramp. Many facilities on site. Details: Mr R. Vicary, 3 Wheatley Lane, Ben Rhydding, Ilkley, Yorks. Tel: Ilkley 607076.

PRIMROSE VALLEY. Fully adapted luxury caravan. Sleeps 6. Bath/shower. Ramp. Many facilities on site. Details: Mr J. Adams, 105 Blakey Close, Redcar, Cleveland. Tel: Middlesbrough 472920.

WESTWARD HO! North Devon. Holiday bungalow, sleeps 6, excellent club, swimming pool, shop on site, near sandy beach. Details (s.a.e. please), Mr G. Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484.

GREATSTONE, Kent. 3 bedroom bungalow. Lounge, kitchen, well equipped large bathroom with hoist. Large garden. Close to safe, sandy beach and shops (200 yds). NE London Association (NELASBAH). Details: Mrs Pierson, 18 Kingsley Rd., London E7 9PP. (Sae please).

SELSEY, Sussex. 6-berth purpose built caravan. Large bathroom. Site with swimming pool and all amenities. Near sea. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton. Tel: Southampton 444921.

SELSEY, Sussex. Purpose built 7-berth mobile home. Fully equipped for wheelchair users. Cot available. Licensed site. Details: Mrs M. Holmes, 11 Grove Road, Ashted, Surrey. KT21 1BE. Tel: Ashted 76730.

CENARTH, W. Wales. Luxury chalet adapted for wheelchairs. Sleeps 6. Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

WINTERTON-ON-SEA, Nr Great Yarmouth. Chalet-bungalow. Sleeps six. Fully equipped. Bathroom—toilet. Accessible for wheelchairs. TV. Shop. Take-away. Club room (live music). Children's play areas. Heated indoor pool. Details: Mr R. H. J. Morris. Tel: 0494 32184.

MABLETHORPE. Two 6-berth chalets, well equipped. Club on site. Fish and chip shop, general stores, cafe. Showers. Outdoor swimming pool. Well kept site, 1 mile town centre. Cannock and Walsall ASBAH. Details: Mr K. Hall, 17 Walhouse St., Cannock, Staffs. WS11 3DY. Tel: Cannock 4847.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access at Brambles Chine, Freshwater. Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle-of-Wight. Tel: 0983 863354.

CHAPEL ST LEONARD'S , Nr Skegness, Lincs.

Specially designed accessible bungalow, in own grounds with children's play area. 4 bedrooms, sleeps 8. TV. Fully equipped. Good local shops and safe beach. Skegness 6 miles distance. Details: Mrs J. Brook, 11 Standiforth Road, Dalton, Huddersfield HD5 9HD. Tel: Hudd. 21776.

LOOE, Cornwall. Self-catering bungalow, suitable for wheelchairs. Sleeps 4/7. Well furnished and equipped. Colour TV. On holiday site with facilities. From £45 per week. Details: P. Cash, Farriers, School Road, Brangore, Christchurch, Dorset. Tel: 0425 72055.

CLACTON ON SEA, Essex. Hylands Chalet Park. 6 berth chalet. Outdoor pool, shop and clubhouse. Equipped with electric cooker, fridge, TV, shower. 5 minutes walk village with supermarket, shops and banks. Tel: Mrs J. Bashford, 01 735 5489.

EXCHANGE & MART

FOR SALE.

Meyra Electric Wheelchair. 24" wide. Little used. Excellent Condition. New batteries: £850. Also metal trailer, little used: £500. Tel: Esher 66276.

Ortho Kinetics Travel Chair. Host of accessories. Very good condition. Cost £700 when new. Sell for £150. Tel: 04023 73495.

Speedwell Supakart. Battery operated vehicle. Hand controlled. Top speed 3 mph. Range 6 miles. Hardly used. Suitable for child or adult. £650 ono. Tel: 0442 69602.

FUNDRAISING? FUNDRAISING?

Printed pens, diaries, balloons, badges, etc. Ideas galore in our brochures. Free sample and price lists from **Shaw Fundraisers, Freepost, Rochdale OL12 7BR. Tel: 0706 342636 (evenings/weekends).**

Enjoy a special holiday this summer away from the crowds at

LYNHALES

Lynhales is a family run Victorian country guest house which has been converted specifically with the needs of disabled guests in mind, offering a wide variety of holidays for disabled people, their families and friends.

Set in 6 acres of private gardens and woodland, over half a mile from the road, we offer peace and quiet in beautiful countryside close to the Brecon Beacons, Wye Valley, Black Mountains and much more.

Country cooking using fresh local produce, an adapted minibus to meet you from the station and for daily outings, a bar and a friendly, informal atmosphere are all part of what we offer.

Off season mini breaks and special interest/activity holidays also available.

OPENING MARCH '86

**LYNHALES, LYONSHALL,
HEREFORDSHIRE HR5 3LN
LYONSHALL (05448) 238**



Directory

of local associations

BARNSELY

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

BEDFORD & DISTRICT

Mrs I Pickering,
Haylands,
41 Box End Road,
Kempston,
Bedford, MK43 8RP.
Tel: Bedford 856992.

BOURNEMOUTH, CHRISTCHURCH & DISTRICT

Mrs G Lanning,
23 Seaway Avenue,
Christchurch, Dorset.
Tel: Highcliffe 3255.

BRISTOL

Mr G Egan,
64 Rookery Road,
Knowle, Bristol 4.
Tel: Bristol 77942.

BROMLEY

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

BUCKS & E. BERKS

Ms S. Smith,
7 Hillcroft Road,
Tylers Green,
Pen, Bucks.
Tel: Penn 5053

BURNLEY & DISTRICT

Mr J Walton,
36 Fairways Drive,
Burnley, Lancs.

BURY & BOLTON

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

CALDERDALE

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

CAMBRIDGESHIRE

Mr R. Wilkie,
Innisiaa,
Mill Lane,
Hemingford Grey, Cambs.

CHESTER & DISTRICT

Mrs P. Itell,
34 King Edward Street,
Shotton,
Deeside,
Tel: Deeside 811074.

DUDLEY & WOLVERHAMPTON

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

ESSEX

Mrs V. Roffe,
11 Withypool,
Thorpe Bay,
Southend-on-Sea,
Essex SS3 8BH
Tel: 0702-584817.

GLOUCESTERSHIRE

Mrs B. Howe,
60 Monks Croft,
Cheltenham,
Gloucs. GL51 7TO
Tel: 0242 32287.

GRANTHAM & DISTRICT

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

GREENWICH

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

HAMPSHIRE NORTH, W. SURREY & S. BERKS

Mrs Liz Selby,
The Old Police Station,
Woodbridge Road,
Guildford.
Tel: Guildford 571736.

HAMPSHIRE SOUTH

Mr S R Baker,
12 Moorings Way,
Southsea, Portsmouth,
Hants. POY 8QW.
Tel: 0705 819075.

HERTS. & S. BEDS.

Mr C. Murphy,
68 Derwent Road,
Harpender,
Herts.
Tel: Harpendor 69630.

HILLINGDON

Mrs B. Brannen,
30 Fairey Avenue,
Hayes, Middx. UB3 4NY.
Tel: 01-573 5488.

HUDDERSFIELD

Mr B. K. Swiften,
7 Jos Way, Shepley,
Huddersfield HD8 8DP.

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 H McLeod,
23 Harvest Ridge,
Leybourne,
Nr. Maidstone, ME19 5LY.
Tel: 0732 840868.

LEEDS & BRADFORD

Mrs P. Robinson,
12 Priestley Walk,
Pudsey, Leeds.
Tel: Leeds 562753.

LEICESTERSHIRE

Mr P. Cusack,
31 Lime Grove, Kirby, Muxloe.
Tel: 0533 393729.

LINCOLN & MID Lincs

Mrs P. Keyes,
Pinfold, Chapel Lane,
North Scarle, Lincoln.
Tel: Spalford 781.

LINCOLNSHIRE

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

LINCOLNSHIRE SOUTH

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

LIVERPOOL

Tudor House,
Wood Lane,
Liverpool L27 4YA.
Tel: 051-488 0246.

LONDON, CENTRAL & NORTH

Mrs Christine King,
30 Derwent Road
London, N13 4PU
Tel: 886 7286.

LONDON N. EAST

Mrs B A Pierson,
18 Kingsley Road,
Forest Gate, E7 9PP.
Tel: 01-472 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,
Ruscote, Banbury.
Tel: Banbury 58124.

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 56686.

ST. HELENS & DISTRICT

Mrs N. Maddocks,
236 Rainhill Road,
Prescot,
Merseyside L35 4LD.
Tel: 051-426 3921.

SALISBURY & DISTRICT

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

SHEFFIELD

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

SHROPSHIRE

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

SOUTHAMPTON & DISTRICT

Mr S. R. Baker (Chairman),
12 Moorings Way,
Southsea, Hants.

STAFFORDSHIRE

Mrs J. Davies,
8 Oakhill Avenue,
Stoke-on-Trent, ST4 5JN.
Tel: Stoke-on-Trent 45365

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

Mr D. J. Lawrence,
69 Woodberry Way,
Walton on the Naze,
Essex CO14 8EW.
Tel: 02556 6245.

SUNDERLAND

Mrs A. Shepherd,
115 Holborn Road,
Sunderland.
Tel: 0783 283 568.

SURREY

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

SUSSEX

Mrs M. White,
Averys, Rusper, Horsham,
Tel: 029 384 217.

SWINDON

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

TRAFFORD & SALFORD

Mrs T. Gaynor,
Moorefield Annexe,
Council Offices,
Crofts Bank Road,
Urmston, Manchester M31 1UD
Tel: 061-748 4000. Ext. 293.
Mornings.

WARRINGTON & DISTRICT

Mr P. Gosner,
22 Sage Close,
Padgate,
Warrington WA2 0UG.
Tel: 0925 819943.

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 Margaret Mort,
27 Park Road,
Hindley, Nr Wigan.
Tel: Wigan 56361.

WIRRAL

Mrs M. Hudson
28 Stavordale Road,
Moreton, Wirral,
L56 9PR.
Tel: 051 678 4409.

WORCESTERSHIRE

Mrs G. Doleman,
9 Pelham Road,
Droitwich, Worcs. WR9 8NT.
Tel: 0905 775862.

YORKSHIRE NORTH

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

OTHER AFFILIATED ASSOCIATIONS

WALES

LLANELLI
Mr P. Williams,
8 Glasfryn Road,
Pontardulais,
Swansea, SA4 1LL.
Tel: 0792 841930.

MID-WALES

Mrs J. Carter,
1 Meadow Road,
Craven Arms,
Shropshire.

NORTH WALES

Mrs E. Boddy,
Canolfan Yr Orsedd,
Fford Orsedd, Llandudno,
Gwynedd. Tel: 0492 78041.

SOUTH WALES

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

SCOTTISH SPINA BIFIDA ASSOCIATION

Executive Officer:
Mrs Audrey Smith,
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.

IRISH ASSOCIATION

Mr Michael Neville,
Old Nangor Road,
Clondalkin,
Dublin 22.
Tel: Dublin 01-572326.

Please will all local Secretaries who want entries changed contact: Mrs Sue Gearing, LINK Editor at National Office: ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01-388 1382.