

Happy  
Christmas  
to all  
readers

# Link

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Association for Spina Bifida and Hydrocephalus (ASBAH)  
22 Upper Woburn Place, London WC1H 0EP

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

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

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**LIFT (Young ASBAH) Organisers:** Miss Ann Monaghan; Mr Andrew Neale    **Link Editor:** Mrs Susan Gearing  
**Manager at Five Oaks, Ilkley, Yorks:** Miss Joan Pheasant, *NNC*    **Development Officer at Five Oaks:** Mr Paul Cooper *BA (Hons)*

## ASBAH Publications

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

Children with Spina Bifida at School (1985) <i>Ed. P. Henderson</i> . . . . . 95p	Five Oaks leaflet. . . . . Free
Young People with Spina Bifida and/or Hydrocephalus — Learning & Development (1985) <i>Leonie Holgate</i> . . . . . £1.60p	<b>Fact Sheets</b> . . . . . up to 10 copies free Translations of fact sheets are available into Bengali, Gujarati, Hindu, Punjabi and Urdu, and into Welsh. <i>Please send at least 30p postage.</i>
The Handwriting of Spina Bifida Children (1979) <i>Joan Cambridge, Eliz. M. Anderson</i> . . . . . £1.60p	<b>Films and Slides</b>
Spina Bifida and You — a Guide for Young People (1985) £3.50p	Appeal for ASBAH (for hire) . . . . . £4.00p + 60p VAT <i>16mm colour film (8 mins)</i>
Sex for Young People with Spina Bifida or Cerebral Palsy (1984) . . . . . £1.75p	<i>Living with Spina Bifida</i> Slide sets and notes (12 slides) . . . . . £7.00 + 75p VAT
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## Editor's Note

On the eve of its 21st birthday, ASBAH is assessing its future role. The recent discussion with local associations at the Annual Conference and Meeting (see pages 6/7) was the start of what ASBAH hopes will be a close and more mutually advantageous relationship with local ASBAHs.

National has a lot to offer by way of services, information, advice, back-up, and many associations are not using it to the full.

ASBAH is aware of the tremendous variation in local associations, and within the next few months wants to be able to build up a clearer picture of what each does, and ways in which it can really help.

In return ASBAH hopes that the local groups will be more prepared to let it have access — in consultation with the local committee — to local coffers which because of their relatively small size some groups cannot tap. This might include, for instance, large local industry. Many associations, quite understandably guard their territory and are wary of intruders. But ASBAH now hopes to make it clear that its so-called 'intrusion' will be in the interests of everyone. Without increased funds ASBAH can't increase its support.

★ ★ ★

ASBAH is busy making plans for 21st birthday celebrations next year. These will include a reception in the House of Lords, and a first ever holiday to America (see page 11). More plans are in the pipeline — see next issue.

**SUE GEARING, Editor**

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**Getting ready for Christmas:** Marcia Dennis, 12, and her 8 year old brother Geoffrey, from Bristol ASBAH, have a look at some of the Christmas cards ASBAH is selling this year. If you'd like to order ASBAH cards this year, there's still time. Send for a leaflet to the Appeals Department at National. There's a really exciting range of cards this year!

# 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 December 5. Send to the Editor at National Office.**

# Getting into the Act. . .

The new legislation, The Disabled Persons Act, won't have any significant effect unless disabled people and voluntary organisations understand their role and act accordingly.

**D**isabled people and voluntary organisations led the battle to get Tom Clarke's Disabled Persons Bill to the statute book.

*It has the potential to be one of the most significant pieces of legislation for disabled people for many years. Implementation of some of the sections started in October this year, but the battle isn't over. The success of the Act depends on disabled people and the supportive organisations. The Act gives rights and opportunities which need to be acted on. Without action, the Act will be worth little more than the paper it is written on.*

*Much of the Act will be determined by Regulations which haven't all been drafted yet. However, certain points are already clear, and voluntary organisations can now be taking them up with local authorities.*

## A SUMMARY OF THE ACT

### PART I

#### Representation and Assessment

##### Section 1: Appointment of authorised representatives of disabled people.

This section is concerned with giving the DHSS power to make regulations about the appointment of representatives for disabled people, who by reason of incapacity, are unable to do so themselves.

The regulations may allow a local authority to ask a voluntary organisation to appoint a representative. There is considerable flexibility in the procedures to be established. The section also allows a parent to appoint a representative for a disabled child.

##### Section 2: Rights of authorised representatives.

The representative may act for the disabled person in relation to the provision of any local authority social service and accompany him to any related meeting or interview. He may have access to information and documents which the disabled person would be entitled to see.

An authorised representative may only be barred from meetings or information if the local authority thinks it would be

harmful to the disabled person. The representative will have access to the disabled person in most types of hospital and residential accommodation.

##### Section 3: Assessment by local authorities of the needs of disabled people.

Before assessing the needs of a disabled person for any social services provision, the local authority must allow him or his representative the chance to make representations. The authority must, on request, provide a written statement of its decision on the needs of the disabled person and the services it proposes, or of an explanation of why it doesn't propose to provide services.

The disabled person or his representative may ask for a review of any decision.

##### Section 4: Services under section 2 of the 1970 Chronically Sick and Disabled Persons Act (CSDP).

This section confirms that a local authority must assess the needs of a disabled person for any of the services listed in section 2 of the CSDP Act if requested to do so by a disabled person, his representative or carer.

##### Section 5: Disabled people leaving special education.

This long and complex section requires the local education authority to inform the social services not later than 9 months before the presumed date the child is to cease full-time education so that an assessment as to his future needs can be made. The social services must undertake an assessment at least three months before the disabled person leaves school or college, unless requested by the disabled person not to do so.

There are sub sections covering sudden decisions and changes of mind about leaving dates and transfer of information if a disabled child moves area.

##### Section 6: Review of expected leaving dates from school or further education of disabled children.

This requires LEAs to keep under review expected leaving dates. The responsibility (under sections 5 and 6) for disabled people in further education is placed on the LEA responsible when the person ceased full-time education at school.

*These two sections (5 and 6) are the first to be implemented.*

# ... Getting into the Act

## Section 7: Persons discharged from hospital.

This covers those who have received in-patient treatment in a hospital for mental illness or mental handicap for a continuous period of at least 6 months.

## Section 8: Duty of local authorities to take into account the abilities of carers.

The authorities must have regard to the ability of carers to continue to provide care on a regular basis when they are assessing the needs of a disabled person for social services. A carer is someone who provides a substantial amount of care on a regular basis at home, and who is not employed to do so.

## PART 2

### Information and Consultation.

#### Section 9: Information.

Social services will now have to inform disabled people who are receiving any

service from them of any other relevant services provided by the authority, by another authority or any other organisation about which they know. (It amends Section 1 of the CSDP Act which only referred to other local authority social services).

#### Section 10: Co-option to committees of persons representing the interests of disabled people.

Appropriate organisations of disabled people must under this section be consulted by a body or committee before it co-opts a member with a special knowledge of the needs of disabled people, which it is required to do so by law.

#### Section 11: Reports to Parliament.

The Secretary of State must provide a

written report each year to Parliament on the development of community services of mentally ill and handicapped people, and on the numbers receiving inpatient treatment.

## PART 3

### Scotland

This provides for the principles of the Act to be applied in Scotland.

(The Act doesn't cover Northern Ireland, but the government has given a commitment to put in hand consultation for introducing an equivalent Act in Northern Ireland).

## PART 4

Sections 16, 17, and 18 round off the Act and deal with definitions, expenditure and the timing of its implementation. The Act is being brought into force piecemeal by the Secretary of State.

### *What voluntary organisations, including local ASBAHs, should be doing*

1) Voluntary organisations should be thinking now about their possible role in providing representatives for disabled people under sections 1 and 2. Most disabled people will know someone who is suitable and who is willing to perform this task. It may be that others will look to a local organisation to advise on this.

2) Local authorities may be considering setting up a small panel to implement the sections dealing with the appointment of representatives of disabled people who cannot appoint themselves. Local voluntary organisations would have a role here,

either sitting on the panel or advising on how it should be set up. It would be sensible to raise this possibility with a local authority at an early stage.

3) Disabled people and their representatives may feel awkward about asking for a written statement of the local authority's decision after an assessment. Local organisations could encourage disabled people to exercise their rights and give them the confidence to do so.

4) Under section 9, local authorities will be obliged to give out information about

local voluntary services *provided that they have it*. They have no duty to seek out this information. Check that your local authority has all the information you would like disabled people to be receiving and that it is available in an easy-to-use form.

5) Many authorities will wait until the Regulations appear before making any preparations for the Act. Voluntary organisations will therefore be discussing the Act with the authority over a period of many months. Patience and enthusiasm for the Act will pay off.

*If you have any queries about the Act or would like to discuss it in any way please do get in touch with ASBAH at National Office — Miss Dot Spence, or Mrs Denise Dunning.*

*A 26 page handbook for voluntary organisations on the Act has been published by RADAR and MIND. It supersedes a previous guide to the Act published in July. Price only 25p for postage and packing, from: RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01 637 5400. (Other rates for bulk orders).*

#### \* STOP PRESS

A Steering Committee of voluntary organisations, including ASBAH, will be drafting Guidelines on how to deal with local authorities over the Act. Authorities will be encouraged to implement the Act, and there will be training for professionals. The Committee will also be discussing the setting up of regional meetings about the Act.

*This article draws on some of the information contained in a report in the magazine of GLAD (The Greater London Association of the Disabled).*

# ASBAH Annual Meeting and Conference

## University of Sheffield, September 5 - 7

**F**OR the first time ASBAH combined its Annual Meeting and Conference into one weekend. The particular aim of the Conference was to discuss the relationship of ASBAH and the local associations.

It was good that many of the larger local associations were represented, and the absence of many of the smaller ones may have reflected the lack of time and resources which these groups often experience. This was something that came up in the discussion. (It is reported more fully in a separate article below.)

ASBAH's new Chairman, Mr Robin Mackenzie paid tribute in his opening remarks at the Annual Meeting to ASBAH's President, the Rt Hon Lord Maybray-King who died on September 3. "I am sure all of us will remember him with great affection" (see LINK last issue for the obituary to Lord Maybray-King).

Mr Mackenzie spoke of the pressures on ASBAH to increase its services and at the same time to find the money to support this work. He said that a new era was dawning at Five Oaks with the building of more independent living units in the grounds in

conjunction with the Sanctuary Housing Association. "I am convinced that helping young people towards independence is one of the most important things ASBAH has to do" he said. Mr Mackenzie also mentioned the importance of ASBAH's Study Days and its support for various research projects.

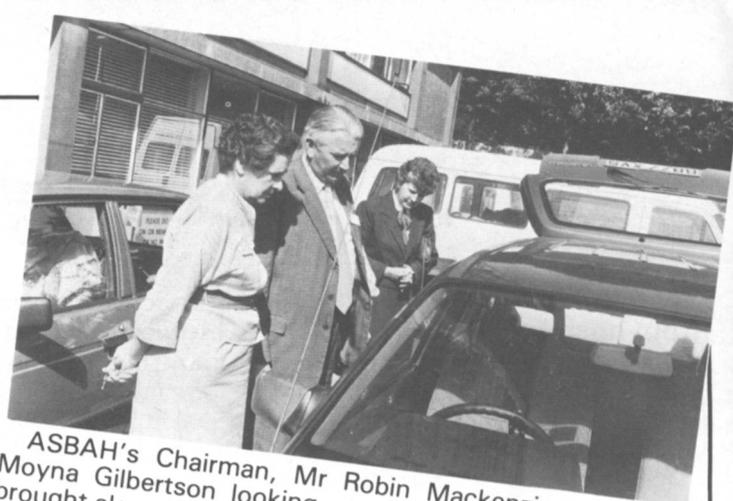
He said that the young people's division, LIFT, was growing in stature. "It is vital that we support it in every way and look at ways in which the young people can be heard more effectively".

During the weekend, Mr Mackenzie had plenty of

opportunity to meet members from all round the country.

ASBAH was delighted that his wife, Lady Jean Mackenzie was able to accompany him. Lady Jean has been a good friend of ASBAH for many years, although she has resigned from active participation as a member of the Executive and other Committees, she remains, as ever, interested in ASBAH's progress, and in news from members.

Lady Jean was presented with a piece of Meissen porcelain in recognition of her support for ASBAH.



ASBAH's Chairman, Mr Robin Mackenzie and Miss Moyna Gilbertson looking at one of the adapted cars brought along to the Conference for members to try.

## The future needs of ASBAH

Opening the discussion about the future needs of ASBAH, the Chairman, Mr Robin Mackenzie said that at the recent working weekend held by the Executive Committee it had become clear that ASBAH has become a significant organisation whose views are respected. But on the threshold of its 21st birthday ASBAH couldn't stand still. There was a need for ASBAH to improve and expand its services and set up a constructive plan for the future. He said that in order for ASBAH to expand it had to raise more money and build up more guaranteed sources of funding.

Mr Douglas Jack, ASBAH's Appeals Director, said that he felt that there was a vast amount of untapped resources in the local association areas. He said he was talking about sources of finance that are not being and could not be

reached by the local associations, but which National ASBAH with its professional expertise might be able to unlock. Any approaches made by National would be done with the full knowledge of and in consultation with the local associations.

After much lively discussion the local associations indicated that such approaches might be possible. It was also felt that there was a basis for a certain amount of sharing of resources between local associations to help those in the more depressed areas.

Local associations said that they would be willing to help ASBAH with its need for more finance, but in return they asked for more accountability. There was appreciation of the work done by National ASBAH, but there was a need for an expansion of services —

more fieldworkers, help with housing, support with the problems of hydrocephalus, new babies, the problems of young adults when parents die, home care, improvement of day centres, the setting up of workshops.

Some associations expressed an interest in regionalisation. The Chairman said: "We did look at the whole question of a regional structure, but it is very expensive". He said it had to be done carefully and it would be necessary to have sufficient finances to support regionalisation and expansion.

It was agreed that ASBAH would contact each local association to find out their needs and to discuss the possibility of tapping local sources of finance. ASBAH would then be in a better position to plan a build up of resources and a structured plan for future development of services.



The informal, social side of any conference is valued by most delegates. Above, Beverley Harris (in the chair) talking to Mrs Margaret White, Secretary of Sussex ASBAH and Andy Neale one of the LIFT organisers.

## Reporting on the year

In her Report on the work of ASBAH over the last year, Miss Moyna Gilbertson, the Executive Director, said that the Association was concerned that so far little results have been shown following Prof. McColl's recommendations and the ALAC Review\*. "However, I am assured that the Report is not being shelved".

She also referred to two other recent reports — Physical Disability in 1986 and Beyond, by the Royal College of Physicians, and the other on Community and Residential Services for 16+. "These three reports together have significant implications for us. And, of course the important work being done by Dr Martin Bax and Dr Andrew Thomas\*\* will provide us with the vital objective evidence we need to press our case in an efficient and professional manner".

Miss Gilbertson mentioned ASBAH's increased involvement with the older age group and with people who have hydrocephalus only. "We also hope to pay more attention to the group of less able young people. We must do more to make professional people in particular aware of different levels of independence and the importance of everyone achieving his own potential."

Study Days have proved a cost effective way of getting across to professionals and parents of meeting new people, reported Miss Gilbertson. "Because we have the good fortune to be able to call on the real experts like Mr Forrest as speakers there is a great demand for our Study Days".

Housing schemes must

have high priority in the future, she said. ASBAH had seriously underestimated the amount of field work support that would be needed by residents initially at least. As a result ASBAH would be trying to inject more money into this service.

ASBAH's revised independence training programme, with the emphasis on local schemes, started during the year, said Miss Gilbertson. "One thing is clear. The local approach only works if we get local support, particularly for making preliminary arrangements. More field workers would, of course, help to alleviate this problem".

Miss Gilbertson said that overseas contacts had increased. ASBAH had had its first full time overseas student at Five Oaks, and there had been more enquiries. The successful International Conference hosted by ASBAH at Manchester University highlighted the importance of access and mobility. . . "It is some comfort to know that our visit seems to have spurred the University on to make some more much needed adaptations".

"Driving courses are now an established part of ASBAH's calendar", said Miss Gilbertson "but once again costs bedevil us. There is no way that these courses can be anything but expensive, but we are trying to condense them, and to find additional sources of funding as we believe there is such a demonstrated need".

Miss Gilbertson said how sorry ASBAH would be to lose the Services Director, Mrs Barbara Newman who



Jean Black, a member of Executive talking to Druscilla Henley who is about to sit in and get the feel of this new Ford Escort Automatic Estate car which was one of several cars at the conference for people to look at.

The car has been given to Surrey and North Hants ASBAH by Caversham Round Table. The idea is that it will allow young people learning to drive the opportunity to have unlimited practice. Banstead Place helped with the adaptations and are going to give the young people some guidance in facing up to the realities of driving and being on their own behind the wheel after passing the test.

The Ministry of Transport has offered members the free use of the track at its Road Research Laboratory at Crowthorne.

The car is available for loan by neighbouring ASBAH's for use by their young members. If anyone is interested they should contact: Mrs Liz Clayton, 118 Overdown Road, Tilehurst, Reading, Berks. Tel: 0734 724013.

was leaving this November. "It has been a real pleasure to work with Barbara for the last 9½ years".

She also gave a personal thank you to Mr Dennis Bryant and Lady Jean Mackenzie for their contributions to the work and development of ASBAH.

● A special scroll was presented to Mr Dennis Bryant on his election as a Vice President of ASBAH. Mr Bryant resigned in March after five very active years as ASBAH's Chairman. ASBAH also welcomed another new Vice President, Sir Hugh Rossi MP.

\*The Review of the Artificial Limb and Appliance Centres.

\*\*The team from the Community Paediatric Research Unit in London is conducting a survey into the Health and Social needs of physically handicapped young adults in the North London area, and the provision for this group. It is being funded by ASBAH.

A copy of ASBAH's Annual Report, 'A Positive Approach' which also contains a summary of the Financial Report, is available, on request, from National Office. A full Report and Accounts is also available.

## Towards £1 million

ASBAH's Treasurer, Mr A K Stewart-Roberts said that in order for ASBAH to expand its services, particularly its field work, it was necessary to try and break through the £1 million income barrier and proceed towards £2 million.

He said that ASBAH

continued to be 'strapped for cash' and long-term planning was very difficult because of the lack of regular income. Legacies were important, he said, and amounted last year to 26% of income, but they were unpredictable, and not a basis for budgeting and planning.

There's more brief reporting from the meeting and conference on page 13.

## Local Association Round-up

### Coventry

**HENRIETTA COLLINS** who wrote to LINK (July issue) about her forthcoming participation in the first World Games for Disabled Youth in Nottingham, returned in September with two Gold Medals for shotput and slalom. She achieved two British records in shotput and discus.

Henrietta said the Games were really enjoyable, with 17 teams taking part.

Also there was **Marcus** (below).

### Sunderland

**MARCUS WAUGH**, right, of Court Leet, Hutton Henry proved to be a real golden boy at the World Games for Disabled Youth — Marcus, 14, won three Gold medals and a commendation.

Sunderland Association have been able to help Marcus in his sporting endeavours by giving him a sports wheelchair.



### Trafford and Salford

**THREE** year old Jaime Hatton of Partington, Manchester enjoying her big day as a bridesmaid.



### Wigan & Leigh.

**ALISON LISTER** and Neil Perkins who were married this year at Sacred Heart Church, Hindley Green, near Wigan. They met at Remploi and now live at a new housing development at Atherton, C. Palentine, opened this year by HRH Princess Anne.



**THESE TWO** women drivers proved that they can be the best by winning the York Institute of Advanced Motorists' Driver of the Year Competition. First was Heather Holden (right) with Faith Seward a close second.

**Faith** who is Secretary of Yorkshire North ASBAH and herself has spina bifida writes about her driving successes below.



Photo: Yorkshire Evening Post.

### WHO SAYS WOMEN CAN'T DRIVE?

I took the Institute of Advanced Motorists test about 15 years ago — in my Mini in Leeds. I passed and told all my men friends who are so rude about women drivers what I had done. Some of them had also passed the I.A.M. test, so I took the 'ROSPA' one and gained the gold award.

The York group of the I.A.M. started 5 years ago, so I moved my membership from Leeds to York. The first York group Driver of the Year test was 4 years ago. I entered in my Metro and didn't win a thing. The following year I had a much larger car, a Triumph Acclaim, and I entered the Driver of the Year competition again. To my surprise, I won the manoeuvrability section of the competition.

The following year I managed a cup and engraved glass by winning the 'Spirit of the Competition' prize. I hadn't won any section or the overall prize but somebody obviously thought I had been a sporting competitor.

This year I entered the competition again. Once again I had a new car, a Rover 213SE. Actually I had only had the car for 3 weeks, so was not expecting much. Wrong again! I was the runner up in the whole competition, 2 points behind the winner (another lady!). The competition consisted of manoeuvrability, a written paper and a test drive with a police driver.

I have been the only disabled driver each time I have entered, but have been given no special treatment for that. We all have numbers, not names, so that the judges do not know who has won until the end.

My car is fitted with full hand controls, but, of course, it is the only way I have ever driven, so that does not worry me. I love driving. I feel quite at home in my large car (perched on cushions, of course, at 4' 10" tall) and, what is perhaps most important to me, I feel equal to everyone else when driving my car. Gone are the mobility problems of difficult, painful, walking and I am as ordinary as everyone else.

I now have another silver cup and a beautiful engraved carriage clock. I doubt I shall ever be *the* driver of the year in York but at least I have shown that a disability need not mean that one cannot compete with able bodied on their own terms and come out top (or nearly)!

## Local Association Round-up

### Chester and District

SPORT and recreation facilities at Dorin Park School, Upton, Chester, have recently been given an additional boost thanks to the support and co-operation of the Chester and District ASBAH.

A specially adapted Pool table which can be adjusted to any level has provided the school with a piece of games equipment which is in constant use and has provided a new 'social' focal point in this school for physically handicapped children. In addition to this, two Ace perception plastic canoes have replaced older well used fibre glass canoes. These new canoes, although of standard specification, are ideal for teaching the disabled to canoe.



Andy Evans on his Three Peaks push.  
Photo: Bradford Telegraph and Argus.

ANDY EVANS, 21, (above) who lives at Five Oaks, recently set himself a real challenge — to conquer the famous Three Peaks (Wharfedale, Ingleborough and Pen-y-ghent). And he did it in fine style in 13 hours 12 mins — just 15 mins more than the wardens in a practice run, without a chair! Andy had the help of local volunteers and the Bradford Countryside

### Bristol

THE RAY MABBUTT Cup presented each year by Bristol ASBAH at the Avon Swift Sports Day for the Disabled was won this year by one of the ASBAH members. He is 15 year old Mark Jewell who won the Cup for the Youngest Endeavour Best Performance of the Day. The presentation was made by committee member, Michael Dennis.

### South Wales

ALISON WOODHAM and her daughter Sophie who has spina bifida took part in a BBC 2 series *The Parent Programme* about the problems and pleasures of bringing up young children. One of the programmes looks at the Care by Parents Scheme\* in Cardiff where parents are encouraged to go into hospital and take over the general nursing of their children. Alison was able to care for Sophie in this way. The 26 programme series starts on November 18 at 2.15pm BBC2 repeated on Sundays at 11.30am BBC1.



Founder members of the Mid Wales and Border Counties Association.

### Mid Wales is 21 this year!

A TALK by Mr Rickham at Alder Hey Children's Hospital, Liverpool in September 1965 brought together four families in the mid Wales area — the Lawrences, McCrackens, Edwards and Carters — all of whom had children with spina bifida and or/hydrocephalus. They decided they would like to try and form a group. In May 1966 a meeting was held for anyone who was interested — a draw took place to cover the cost of refreshments and a profit of 18s (90p) was made. The Mid Wales and Border Counties Association was on its way! It became a registered charity shortly afterwards.

The association at the time covered Shropshire, Herefordshire, Merioneth, Radnor and Montgomery. Katherine Elliott School became the association's permanent home for meetings. The first Christmas Fayre in the Winter of 1966 raised £250, and there followed parties, outings and more fundraising.

In 1970 the association acquired a holiday caravan at Borth. The demand was so great that members were only able to book one week in the school holidays every other year.

It was in the 1980s that in order to give a better service three independent associations were formed — Shropshire, Herefordshire and Mid Wales. Later Shropshire split again to form Whitchurch (Shropshire). Now in 1986 there are still three independent associations — with only Hereford closed through lack of support.

Mrs Joan Carter, Secretary and one of the founder members writes: 'Over the 21 years, governments and local councils have been coerced, bludgeoned, and sometimes even war declared, to get increased benefits, improved schooling, better access and housing. . . and the association can be proud of its achievements. More work remains to be done. The babies for whom our association was formed are now adults, living independently, driving, marrying, and playing their part in society. The independence they have achieved has exceeded everyone's wildest dreams. Here's to the next 21 years!'

*\*Care by Parents will be on Feb 3.*

### Taking up the Challenge

Warden Scheme to complete the 23 miles and get sponsors.

Forty people, split into five teams, helped him over steep climbs and bogs.

Congratulations to Andy, who raised about £2,000 for Five Oaks' courses and earned himself a place in the record books.

**T**here have been a number of staff changes in recent weeks at National ASBAH.

## Services

It is with great regret that ASBAH has said goodbye to its Services Director, **Mrs Barbara Newman** (see a note from her below), and sends best wishes to her and her family for their new life in Ethiopia.

### FROM BARBARA NEWMAN, SERVICES DIRECTOR WHO LEFT ASBAH IN NOVEMBER.

*I would like to take this opportunity of saying 'goodbye' to all the many friends I have made throughout the country in the 9½ years that I have worked at ASBAH. There have been many changes in the structure of National ASBAH since I joined, and I feel ASBAH has been getting ready to move one step further in it's development. I would like to say a special 'thank you' to all the Local Associations and families all over the country who have welcomed me into their homes during visits. I shall miss all my friends at ASBAH, and wish everyone well for the future.*

*I am moving with my family to Ethiopia for a year and look forward to the different and exciting challenges this will bring. I hope to keep in touch and look forward to receiving my copies of LINK and LIFT.*

## ASBAH NEWS

**ASBAH welcomes Miss Dorothy Spence** as the new Services Director. She comes from the Health Service in Harringey where she was involved in organising community health services for the whole population. She has had contact with disabled children and disablement organisations during her work in the health service, notably at Liverpool Children's Hospital and UCH.

## Disabled Living

It has been a sad farewell also to one of the Disabled Living Advisers **Miss Mary Small** who will have met so many members round the country during four years with ASBAH. Mary has packed a huge rucksack and set off to do some travelling.

Mary made a great contribution towards informing families of the many benefits, equipment and facilities available, and in advising on personal care.

Mary Small's successor will be announced shortly.

**Miss Clare Michelmore** is now **Disabled Living Advisory Coordinator.**

## Administration

**Paul Dobson** is now **Assistant Director - Administration.**

## Public Relations

**Madeleine Legg**, Public Relations Manager, has left this position to move down to Dorset with her family. Madeleine became responsible for all aspects of Media relations and ASBAH's public image when the Press and Public Relations Department was set up in April 1985. She was very successful in attracting a good deal of media interest and exposure for ASBAH in a period of just over one year.

Madeleine joined ASBAH in 1978 as a Regional Fundraiser for Surrey, Hampshire and Berkshire, working closely with local associations and National Office. She moved to National Office two years ago as a national fundraiser.

Madeleine hopes to build up freelance work from her home in Dorset, but in the meantime continues to do some work for the PR Department to support the new PRO, **Miss Sarah Pracey**, who has joined ASBAH after gaining a Class II Degree at King's College, London.

## EXECUTIVE COMMITTEE

**Miss Faith Seward**, who for so many years supported ASBAH as a member of the Executive Committee has resigned. A new member of Executive is **Mrs Lorraine Goodman** from the Cambridgeshire Association. She was a Council member for five years.

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Especially for ASBAH's 21st Birthday celebrations next year . . .

## **LINK readers' special two centre USA Holiday. October 1987**

Arrangements are now complete for this first ever LINK readers' holiday to take place in October 1987.

There has been a terrific response. Those who asked for more details should now have been sent the full up to date itinerary, prices and a booking form. If anyone missed the announcements in the last LINKs there is still plenty of time to send for full details and a booking form. Contact: Mr J. Brown, Panovista, 78 Sea Road, Sunderland, SR6 9DB. Tel: Sunderland 0783 494445.

*There will be two two week holidays:*

*Flying from Gatwick, Sat. October 3-Sunday October*

*ing from Manchester, Sat. October 17-Sunday November 1.*

Travelling with the party will be a number of helpers who will give assistance to lift wheelchairs on and off the coaches.\* A member of staff from ASBAH will also travel with the party.

All the hotels and attractions listed have been visited by Mr Brown of Panovista and are accessible..

Single people travelling on their own might be willing to share a room with someone else in the same situation to save single room supplement charges.

The holiday is not confined to LINK readers; friends and relatives are also warmly welcomed. Anyone travelling alone should be able to cope with their own personal care. The ASBAH representative will only be able to give very limited assistance.

The two centre holiday includes 10 nights in Orlando close to Disneyworld and a number of other attractions, followed by 4 nights at a hotel on Clearwater Beach on the Gulf of Mexico to unwind after all the sightseeing. The cost of the holiday includes entry to Disney World and the Epcot Centre (3 day pass), to Seaworld, to Cypress Gardens, and a day visit to NASA, entry to Bush Gardens, and a 3 hour cruise. It also includes flight by British Airways 747 Jumbo, coach transfers to hotels, airports and attractions. There is also a range of free flight services etc.

## **Fortnight in Florida**



*In the sun at Clearwater — some of the young people enjoying the Sunderland ASBAH holiday to Florida in 1985 — on which this LINK readers' holiday is based.*

The price of the holiday to include the attractions listed is £678 adult (sharing a twin bedded room), child (under 12, sharing room) £440. There are deductions for 3rd and 4th adult sharing, and single room supplements.

The price of food is not included, but is considered to be better value for money than in Britain. There is a big choice of restaurants and snack bars to suit all pockets.

*For more information contact Panovista (address above) or Mrs Sue Gearing, LINK Editor, at National Office. Home tel. no: 0934 862279.*



## **Letters**

The sudden death of PC. Philip Olds has, once again, brought the plight of the disabled to the attention of the media. The tragic circumstances which left PC. Olds paralysed has caused thousands of disabled to write to their organisations for more information on his new American Walking device. Unfortunately, the press did not give

equal coverage to the 250 spina bifida children now walking with the British Made Oswestry Splint, the Parawalker — also known as Hip Guidance Orthosis. Nor did they realise that over 50 adults with traumatic spinal injuries (usually motor-cycle accident victims) use the British device nearly every day.

Research is still continuing, particularly where adults are concerned, but the junior device is now available through the NHS.

Because this device is tailor-made to each individual, special Centres have been set up to assess each person before measurement. After final fitment each

person is taught to sit, stand, walk, negotiate kerbs or steps, to don & doff. A list of Centres and an information leaflet can be obtained from me.

The DHSS has done a fine job in pioneering and funding the development of the Parawalker at their research centre — ORLAU of the Robert Jones & Agnes Hunt Orthopaedic Hospital.

Yours faithfully  
**B.M. SHOLES,**  
**Managing Director, PARAD,**  
**Weston Lane, Birmingham,**  
**B11 3RS**  
**Tel: 021 706 3936**

by  
**Lauren Kerzin-Storarr and  
Dian Donnai,**

Department of Medical  
Genetics, St Mary's Hospital,  
Manchester

**M**ANY people with spina bifida themselves, or a relative with spina bifida, worry that their own children could be born handicapped. If this is something that you have wondered about, then you may wish to have *genetic counselling*.

### What is genetic counselling?

*Genetic* comes from the word *gene*, and genes are the hereditary factors which parents pass to their children at conception. We all have thousands of genes including a few faulty ones. Sometimes a faulty gene can cause illness or handicap. So, genetic counselling is counselling about the hereditary factors in a given disease or handicap.

Genetic counselling aims to help you understand:

- *what is known about the cause of the disability*
- *what the chances are that your children could be born with the same problem*
- *what can be done to prevent it happening*
- *what choices are open to you.*

Genetic counselling will *not* tell you whether you should or should not have children. That is a very personal decision which only you and your partner can make. Hopefully genetic counselling will help you to make the choice which is best for you.

### Who provides genetic counselling?

**Genetic counselling is usually given by doctors with a special training in genetics who are called *clinical geneticists*. Most regions in Britain now have at least one clinical geneticist, usually based in a teaching hospital. Some do clinics in hospitals in smaller towns, so you may not have to travel far.**

### How can you request an appointment for genetic counselling?

Either your GP or hospital specialist can refer you to the genetic counselling clinic nearest to where you live. You may feel like asking for genetic counselling now, or you may wish to wait until you are planning to be married and bring your partner with you.

# Genetic Counselling

## For young people with spina bifida and their families

### What will happen?

— Before the clinical geneticist can discuss the chances of your children having spina bifida, he or she will draw a family tree — called a *pedigree* — and will want to see the hospital records for anyone in the family who has spina bifida or a related condition.

The doctor may also wish to examine you and in some instances, arrange for further tests such as an X-ray. When all the information is to hand, there will be plenty of time to discuss your questions and worries. The genetic counselling clinic allows more time for each appointment than most outpatient clinics, so you needn't feel rushed and hurried. The clinical geneticist wants to be sure that you understand what has been said, and that all of your questions have been answered as far as is possible. In some genetics centres, a nurse or counsellor will offer to visit you at home following your clinic appointment to go over the information you were given.

### What am I likely to be told?

Every individual or couple who comes for genetic counselling is assessed personally. The risk of your having a child with spina bifida is calculated after considering several factors. These include:

- *How many people in the family have or had spina bifida*
- *how these people are related*
- *what other handicaps, unusual features, or medical conditions are in the family.*

Rarely spina bifida occurs together with other separate handicaps and in these cases may be due to a faulty gene, a

chromosome problem, or may not be inherited at all.

Most of the time, however, spina bifida occurs without other handicaps (except those directly resulting from it including hydrocephalus, lower limb problems or bladder dysfunction). In these cases the cause is thought to be *multifactorial*, which means that many factors (both in the genes and in the environment) contribute to spina bifida happening.

**This means that if you or a close relative has spina bifida, then your chances of having a child affected will be higher than it is for people without spina bifida in their family. However, even when more than one person has spina bifida in a family, the chance of having a healthy child is usually much higher than having a child with spina bifida.**

There are several ways of lowering the risk of having a child with spina bifida. Some studies have shown that by taking special vitamin tablets from the time before conception until the second month of pregnancy, couples with a family history of spina bifida can reduce the chances of the child being affected with spina bifida. Although this has not yet been proved conclusively, the clinical geneticist will discuss this with you, and give you and your doctor the details of which tablets need to be taken and when. (They are, unfortunately, no longer available on the National Health.)

It is also possible to tell if an unborn baby has spina bifida using many different tests including blood tests on the mother, amniocentesis (a sample from the waters surrounding the baby), and ultrasound scans of the developing baby to look at its spine. Using these

**Briefly . . .**

techniques it is possible to detect about 90 out of every 100 babies with spina bifida, during pregnancy. Most of those not detected would be less severe cases.

Unfortunately, if the unborn baby is shown to have spina bifida, it is not possible to correct the defect in the spine. The parents have the option of an abortion if this is what they choose. This is obviously a very personal decision which each couple must decide for themselves. The dilemma of whether or not to abort a baby with spina bifida can be an especially difficult one for people who themselves (or someone dear to them) have spina bifida. It can be confusing to think of aborting a spina bifida pregnancy while still valuing the existence of people with spina bifida.

It is important that you discuss your feelings with your partner, the genetic counsellor, and your obstetrician before making a decision. You may also find it helpful to talk with your family doctor or clergyman, as they will perhaps know you well. In the end, there is no "right" or "wrong" decision, but most people who think carefully before making a decision, find they can live with their choice later.

**What options will I have?**

**When deciding about whether or not to have children, you will add the information given to you by the genetic counsellor to other factors which all prospective parents have to think about. These include your financial state, housing situation, and how you consider you could physically cope with the demands of parenthood.**

There are three main options which couples with a risk of spina bifida may choose:

- 1 *Having children without any special tests in pregnancy and accepting the usually small risk that the child could have spina bifida.*
- 2 *Trying for a family, but having prenatal tests which would detect spina bifida early in pregnancy. (Both 1 and 2 include the possibility of prevention using the vitamin treatment mentioned before.)*
- 3 *Deciding not to have children (adoption or fostering may be an alternative).*

Some people find that they change their minds about having children, as they grow older. Hopefully, genetic counselling will at least provide you with information about the risks — and possible prevention — of spina bifida, to help you reach the decision which is right for you.

● Dr Roger Bayston spoke at the Conference about the causes of hydrocephalus, and in particular of the growing numbers of premature babies who develop hydrocephalus. He said that 90% of people with spina bifida have some hydrocephalus.

● Dr Andrew Thomas, a research psychologist from Charing Cross and Westminster Medical School spoke about physical handicap and the transition to adulthood. A report on his paper will appear in the next LINK.

● In a session on mobility, ASBAH's Mobility Adviser, Leonie Holgate said that a young person wishing to learn to drive should apply for a

provisional licence at least 3 or 4 months before his or her 16th birthday as there was often quite a wait. Once a young person with spina bifida and or hydrocephalus had learnt to drive their problems weren't always over. Mrs Holgate was particularly concerned at the difficulty faced by many in finding their way about. Research was being carried out into this at Banstead Place Mobility Centre in Surrey.

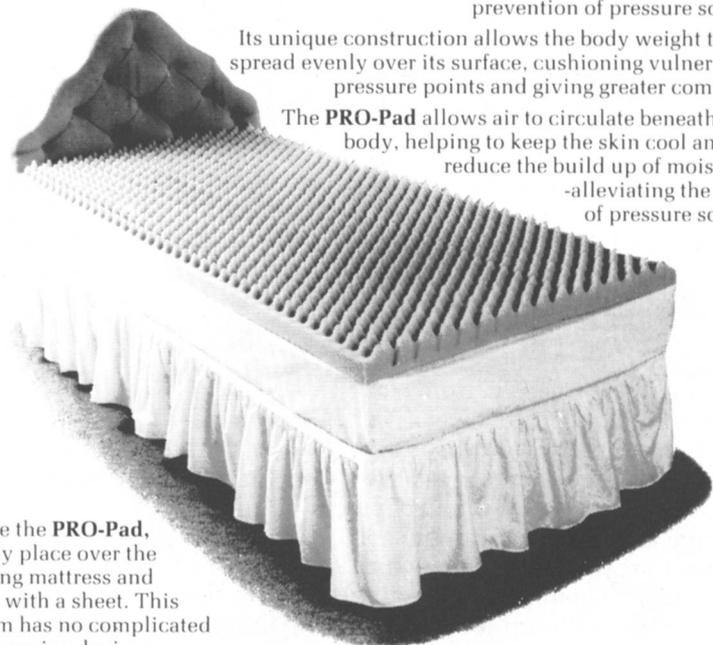
● During a discussion group of the use of the media, local association expressed interest in ASBAH setting up a workshop on making the most of the media. ASBAH hopes to be able to arrange something on these lines if there is sufficient interest.

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**I**f you drive away from Worthing seafront down Grand Avenue past elegant family homes, you probably wouldn't notice anything special about No. 5 — except perhaps for the ramp to the front door.

It has been beautifully painted and decorated and looks a well cared for, welcoming home. In fact, that's just what it is. But it is also a home that is a bit special. It's a 'stepping stones' home for eight young people with spina bifida and/or hydrocephalus.

No. 5 Grand Avenue is the culmination of six years' planning, negotiations and hard work by Sussex ASBAH. It opened its doors in June this year and will be visited by the Princess of Wales this Winter.

Here up to nine young people can live for a few years and learn to acquire the skills of daily living. When they feel confident they will move on to more independent homes of their own.

When LINK visited, seven young people from the Sussex area were in residence — Kevin Towner, Paul Cooper, Jane Denness, Mandy Brooks, Lorri Boxall, Chris Rendell and Joanne Toubkin. Another, Simon Evans was about to join them.

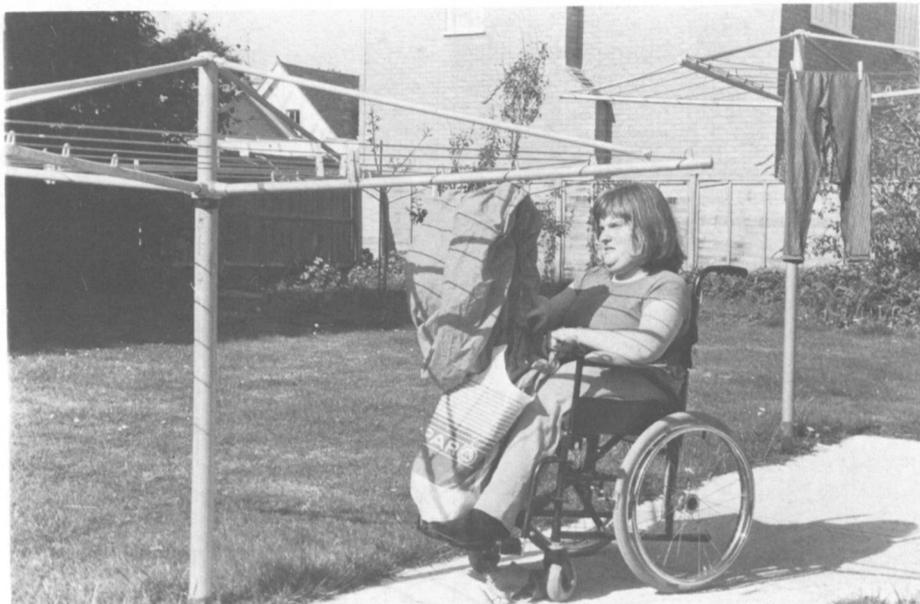
They were all known to Sussex ASBAH except for Chris. She had continued to be mailed with information and newsletters by Sussex ASBAH, but hadn't made contact for many years. Then she responded when she received a letter from them to say that the Association was looking for young people for Grand Avenue. She had wanted to make the move away from home and Grand Avenue seemed ideal.

All the young residents chose their own curtains, furniture, soft furnishings, china, pots and pans. As can be imagined their tastes vary enormously, from black curtains to a pastel coloured duvet cover!

Each has his or her own bedsit. Five rooms share a large kitchen and two bathrooms and toilets. Two other rooms share a large kitchen and bathroom and upstairs there are two more rooms which are intended for more mobile young people, like Kevin. These rooms share a kitchen and bathroom. In addition there is a flat for Carolyn Atherton, the Training Officer in charge, and there is a laundry area too.

Instead of a formal communal lounge it was decided to create a communal area off the kitchen. "After all, at home, it's usually the kitchen where people like to gather, isn't it?" said Margaret White, Sussex ASBAH Secretary.

When LINK visited, several young people were there having coffee and discussing religion with Annette Stapleton. She is an Open University



Joanne Toubkin putting out the washing.

## No. 5 offers a whole new lease of life

volunteer who comes in to initiate discussion and projects and to get people thinking.

There are also five Personal Care Advisers under the Community Programme, working alongside the residents as friends. The other member of staff is Marion Knight, Deputy to Carolyn.

Margaret White said: "We had been in contact with a housing association for a long time and getting nowhere when we were introduced, through a friend of a friend, to Downland Housing Society, who had already been involved in a housing project for people with mental handicaps. They arranged a meeting with us and were very enthusiastic . . ."

Downland bought and adapted 5 Grand Avenue with Housing Corporation Finance, and their architects, BDC (Building Design Consultants) from Worthing, altered and adapted it in consultation with Sussex ASBAH. "Downland and BDC have both been extremely helpful" said Margaret.

The house is classed as a hostel. Sussex ASBAH is the tenant and the young people are licensees. Using benefits and allowances the residents each pay their

own rent. Sussex ASBAH is responsible for paying the heating and staff costs and Downland is responsible for maintenance.

There was some trepidation from the neighbours when they first heard about the proposal, but they were won over after being invited in to see and discuss the plans. Once it was opened there was an Open Day which proved very popular, attracting 150 visitors. Now No. 5 seems to have been accepted as a welcome part of the area.

The young people are gradually getting more involved in the community, joining local clubs such as Rotaract and Phab, going to evening classes, bowling, etc., and as a group they visit an old people's home to chat to residents. Local organisations have proved supportive — the Lions and TVS gave financial help. Rotaract members planted flower beds and built raised beds in the garden.

A really big boost came earlier this year when it was announced that Sussex was to be given an EEC Grant of £16,000. "We were delighted. We hadn't really thought our application would get anywhere" said Margaret.

It hasn't all been smooth sailing. There have been many disappointments and frustrations and the feeling that it would never actually happen. There were teething problems too when the residents first moved in. Once the initial euphoria had worn off, some of them found that the reality of living away from home was quite hard to take. But life is settling down now into a routine with everyone starting to make his or her own way and working together as a group.

It's a question of learning to live with each other and themselves.

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L. T. D., Staffs

'I have had MS for 40 years and been plagued with complete incontinence for that period, but the Freedom Sheaths are by far the very best I have used in that time.'

A. W., Hendon

'These are the best I have ever used – and I've tried a few!'

E. R. T., Littleborough, Lancs

'My husband has found the Freedom Sheaths highly satisfactory, some of our friends with spinal injuries are now using them. We will certainly educate more disabled people who have problems on how easy the new sheath is.'

Mrs E. M., Dundee

'We have tried several designs of sheaths in the past, and to date the Freedom Sheath is by far the most satisfactory all round.'

Mrs M. N., District Nursing Sister  
Ashford, Middlesex

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## HYDROTHERAPY POOLS

This little girl is obviously enjoying her own hydrotherapy pool.

Hot Water Reservoirs is a firm producing such pools — suitable for homes, schools, small units. The cost is about £1,500 - £2,000 plus VAT and installation. Mr David Hirst representing the company explains:

“Our sister company, Northumbria Swimming Pool Services Limited, has been building swimming pools for over eight years. Hot Water Reservoirs Limited has been set up in a new factory to concentrate on the manufacture and sale of hydrotherapy pools. We first became aware of the need for hydrotherapy pools about a year ago when asked to help a family in North Yorkshire. They have a handicapped daughter and wanted to provide her with the benefit of a hydrotherapy pool in the comfort and convenience of her own home. Up until now they had been ‘trekking-off’ down to the local swimming baths on a daily basis, which was far from ideal in many ways. All we could do to help them was ‘fit-out’ a 5ft milk churn they had acquired from a local farmer. However, seeing the dramatic effect exercising in hot water had on this girl, we set about designing a pool specifically for home use; something many people could benefit from, not just the one.

“By using modern materials and the latest swimming pool techniques we have developed a hydrotherapy pool which can be built to any size, assembled either in or above ground, is easy to install, relatively inexpensive to buy and cheap to run. It is delivered in flat-pack form, so that it can go through any difficult doorways, and is assembled in position without any complicated wiring or plumbing. If, in the future, the person should move house it can be dis-assembled and taken with them. The principal has also been scaled up to ‘conventional’ pool sizes and since we can reduce the typical installation costs by about 50% we have had a very good response to this development.”

For more details contact Mr Hirst at Hot Water Reservoirs Ltd., 15/16 Gatehouse Industrial Estate, Berry Edge Rd., Consett, DH8 0ND. Tel: 0207 591305.

## WHEELCHAIR ANTI-ROLL DEVICE

A safety device which prevents self-propelled wheelchairs from rolling backwards has been invented by 19 year old Andrew Lavender, a student. It won him a major award in the Engineer for Great Britain competition.

The device is easily fitted to the chair, using existing screw holes and when in place gives the user confidence and safety. The restraint automatically comes into use should the wheelchair start to roll backwards.

When attempting to get up a ramp, hill or difficult slope in a chair something like this device would prove invaluable.

The device costs £30 a pair (for both wheels) including p & p, from: W.A.R.D. Engineering, The Old Post Office, Minera, Wrexham, Clwyd, LL11 3DA.

# Daily Living

## THE TRANS-SIT SEAT

**The Tran-sit seat, a very simple device for carrying or transferring someone who is disabled, has been personally recommended by a family in Oxfordshire.**

Mrs Jean Madley of Drayton writes.

“We have found the Trans-sit seat invaluable for taking our daughter Elaine to places where a wheelchair cannot get. On and off coaches, up and down stairs or steps. Most important for Elaine, down to the sea over sand when we are on holiday.

“The seat is supplied through the Social Services — ask your occupational therapist. A harness can also be obtained, which fits round the person or persons carrying to leave their hands free.

“It is a very dignified way for an adult to be carried.”

**So LINK got in touch with the manufacturers, Ellis, Son & Paramore.**

**There are two sizes to fit adults and small children; or medium and large adults, and as Mrs Madley said, optional adjustable shoulder straps (for long or heavy lifts) are available.**

**The seat is made of a strong washable synthetic fabric with a padded seat for added comfort and folds flat for storage or packing.**

**The person in the seat is held securely at a slight backward tilt so he or she can be lifted by two handlers in comfort. The chair is fitted with a strong fabric waist belt to be used at all times.**

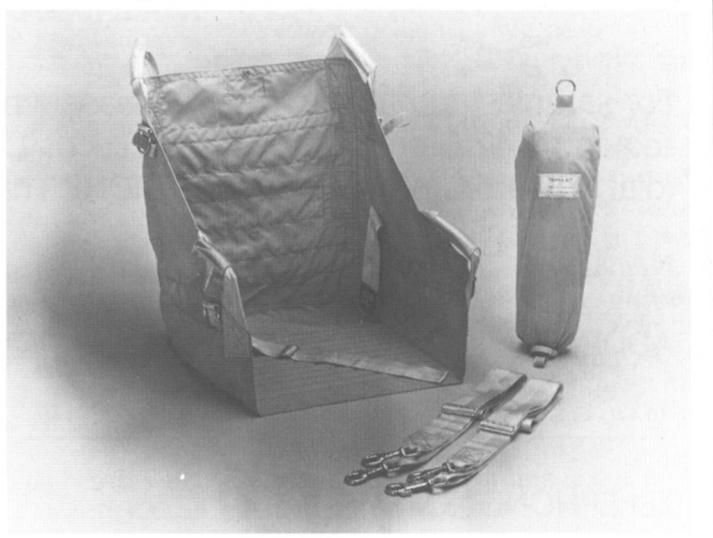
**Special features include drainage holes for use in pools, four comfortable side lift handles and extra webbing handles for front-back lifting.**

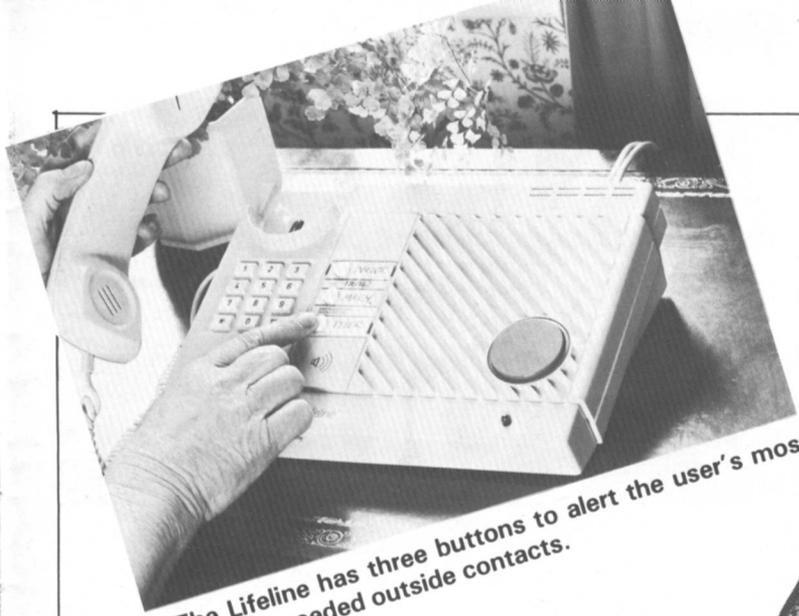
**The seat can take someone of over 17 stone under normal transit conditions.**

**It should be possible to obtain the seat through your Social Services department.**

**To buy, it costs £28.16 (large), £27.50 (small) shoulder straps £4.91 pair. Postage and packing £2.00. Its zero-rated for VAT.**

*More details from Ellis, Son & Paramore Ltd, Spring Street Works, Sheffield S3 8PB. Tel: 0742 738921.*





The Lifeline has three buttons to alert the user's most frequently needed outside contacts.

## A Lifeline for those who live alone

If you are a disabled person living on your own you might feel much more confident and secure if you knew that you could summon up help in an emergency at the press of a button.

This is a practical possibility thanks to the Piper Lifeline — an emergency call system which can be answered 'remotely' by pressing a body-worn button. It can be linked to control centres all over the country.

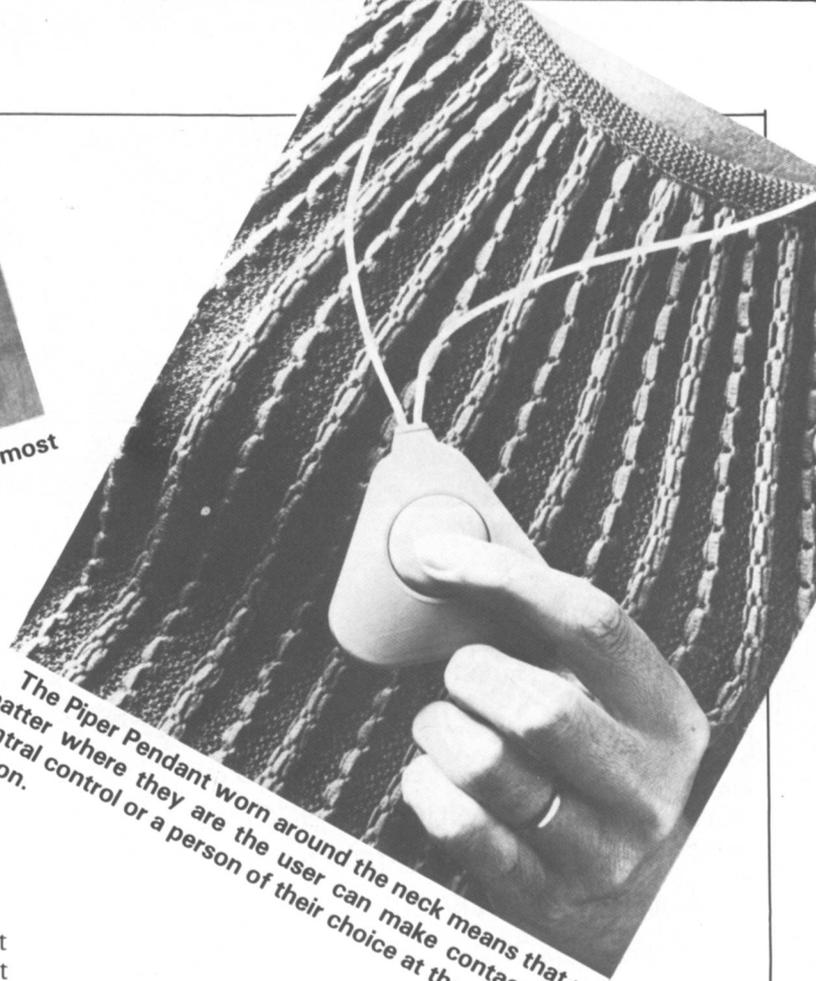
Tunstall Telecom — who pioneered elderly people's emergency call systems — have launched Lifeline. Used together with their Piper Pendant — a body worn radio trigger — Lifeline opens up a two way speech communication channel with the control centre at the press of a button. The centre is on 24 hour call — using mobile and other units — to provide emergency aid. Your Lifeline can also be programmed to link up with three other numbers of your choice — perhaps the doctor or a close relation.

A feature of Lifeline is that it also operates as a normal telephone — but a telephone with a plus. It enables you to answer a call and conduct a conversation simply by pressing the pendant, even if you are some distance from the unit. This is made possible because of the high quality built-in loudspeaker and sensitive microphone system.

As well as being programmed to dial the three most regularly used numbers at the touch of a single button, Lifeline can be programmed up to eight further numbers for two-key manipulation on the normal key pad beneath the receiver for fast contact with family members, friends or services. Any other calls can be made in the conventional way.

Piper Lifeline is easy to connect, requiring only a 13 amp 3 pin electrical mains outlet and an ordinary new-style telephone socket. In the event of mains failure, there is a dry battery back-up system.

There are over 110 local authority control centres you can link up to, and in the South (roughly the area covered by Southern TV) there is a control centre set up by Tunstall Telecom, and in the North another based at Whitley Bridge, Yorkshire. So the first step is to find out if your local authority has a control centre and ask if you can be linked to it.



The Piper Pendant worn around the neck means that no matter where they are the user can make contact with central control or a person of their choice at the press of a button.

Your local authority may well help with the cost and Help the Aged is also doing what it can to finance people through its Lifeline Appeal.

The Lifeline system can be hired through any branch of Boots the Chemists. Rental and connection to the control centre is currently £14 per month. The minimum hire period is 12 months and the first three months' payment of £42 is payable on installation. Tunstall will install the system with the minimum of delay and have an after sales and servicing team. Boots are demonstrating the equipment in some large branches and any branch will make arrangements for a demonstration in the privacy of your own home. It is possible to buy a complete unit — at about £290.

For more details contact Boots, or Tunstall Telecom, Whitley Bridge, Yorkshire DN14 0HR. Tel: 0977 661234.

### INTRODUCTION TO DISABILITY BENEFITS

#### THREE DAY PUBLIC TRAINING COURSE

January 27, 28, 29, Non Residential

Conference Centre, 336 Brixton Road, London SW9 7AA  
(fully accessible)

This Disability Alliance course is aimed at those with some familiarity of social security, but with limited experience on disability benefits.

It will cover: The structure of the welfare state, claims, payments and appeals, incapacity benefits, supplementary benefit, hospitalisation, mobility, attendance and invalid care allowance and special compensation schemes.

The fee is £80. (Reduced prices for underfunded voluntary organisations.)

For details contact the Training Assistant, Disability Alliance ERA, 25 Denmark Street, London WC2 8NJ (01-379 6142). Closing date for bookings — January 14.

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\_\_\_\_\_

● A special study on discrimination against disabled people in employment has been launched by the Spastics Society. The research project provided hard evidence that disabled people are not given an equal chance. It was found that able-bodied applicants were over one and a half times more likely to receive a positive response than their disabled counterparts.

The findings of this report are disturbing especially considering that at initial application the extent of the person's disability was unknown and that it was emphasised that the disability had not restricted the person's career development.

Copies are available, price £1.50 from The Campaigns Department, The Spastics Society, 12 Park Crescent, London W1N 4EQ.

● The Banstead Place Driving Instructors' Support Fund has been set up to give financial help with car adaptations to young people who have had assessments at Banstead and are having trouble finding enough money for an adapted car. The Fund was set up by a group of instructors attending a course at Banstead.

Although in its infancy the fund has already started to help young people, and was recently boosted by a big donation after the Drivex Annual Rally at Silverthorne. Visitors paid £5 to be driven round the track in a car like a Ferrari and the money went to the Fund. Thanks to the generosity of the drivers who waived their fee, and the Driving Instructors Association who paid for the petrol the Fund was boosted even further. For enquiries about the Fund contact Banstead Place Mobility Centre, Park Road, Banstead, Surrey. Tel: 073 73 51674.

● RADAR — the Royal Association for Disability and Rehabilitation — has introduced an Insurance Scheme for disabled people

## Newslines NEWSLINES Newslines



in conjunction with Sun Alliance, for details contact Anne Cox at RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01 637 5400

● The Royal Opera House, Covent Garden, London now offers increased access for wheelchair patrons. Twenty wheelchair spaces are available for specific ballet and opera performances at £10 each with one accompanying ticket also on offer at £10. Some of the forthcoming performances include a triple ballet bill on December 17, the opera, Samson, on December 16, and Lucia di Lammermoor on January 5.

The new facility is possible through sponsorship from Paul Hamlyn. There has always been access to the Opera House — limited to two spaces per performance, with seats available for people who can be transferred from their wheelchairs once inside the auditorium.

These will continue to be available at all performances. For full details and a booking form contact Camilla Whitworth-Jones, Royal Opera House, Covent Garden, London WC2E 9DD. Tel: 01-240 1200.

● Central T.V.'s *LINK* programme is now screened on Sundays, Tuesdays or Wednesdays: Sunday at 1pm for viewers in the Central, Yorkshire, HTV, STV and Ulster regions; Sunday at 1.30pm for LWT, Border, Grampian and Tyne Tees; Tuesday at 12.30 for viewers in the TVS, Channel and TSW regions; and Wednesday at 12.30pm for Anglia viewers.

● Surrey is to have one of the first purpose-built units in the country for the care and support of severely disabled people. Work has begun on a £1.3 million, 20 bed home — Harrowlands — adjoining Dorking hospital. It is expected that the unit will be used by the younger physically disabled in East and Mid Surrey. It will provide 16 single bed-sits, two doubles, physio and occupational therapy facilities.



Contact a Family is setting up a new telephone line for handicapped children and their families. It will be manned by parents and volunteers and will offer information and advice in a personal and appropriate way. The Contact Line will not be a crisis or counselling service but will link families, groups and statutory and voluntary organisations. The target for setting up Contact Line is ¼ million and funding is well under way.

Contact a Family is a national charity which for 12 years has been working with families with a child with special needs.

It encourages families to form local self-help groups, puts individual families in touch with each other, and provides an advice and back up service.

For more information Contact a Family is at 16 Strutton Ground, Victoria, London SW1P 2HP. Tel: 01-222 2695.



### STUDY DAY IN NORTHERN IRELAND

ASBAH is holding a Study Day in Antrim on December 4 on all aspects of spina bifida and hydrocephalus. It should be of interest to both parents, young adults, adults and professionals. For details contact: Mrs Denise Dunning, at National ASBAH.

**PAYROLL** giving will become a reality in Britain next year. Here ASBAH's Appeals Director, Douglas Jack gives his views on this new form of giving.

## Give as you earn: will it bring much change?



The Chancellor in hopeful mood after he had announced payroll giving in the last Budget.  
Cartoon by Gus.

**A** LARGE amount of printer's ink has been used in comment on the provisions relating to charities in the 1986 Budget. The question of payroll giving has probably received more attention than all the others put together.

The Director of the Charities Aid Foundation is on record as saying that the Budget, and especially payroll giving, are likely to be responsible for raising £50 million pounds of new money over the next few years.

Surely an irresponsible statement if ever there was one. What are the facts about this new alleged gold mine?

The Finance Act of 1986 says that from April 1987 an employee can have deducted from his pay up to £100 a year to be given to a charity of his choice. His or her donation will be deducted like his or her contribution to an occupational pension scheme, from gross pay before tax, so that, in effect, at the present standard rate, his £100 will cost him or her only £71 with the other £29 coming from public funds.

The money will be paid over by his or her employer not directly to the selected charity but to a recognized charity agency which will be responsible for the distribution in accordance with the donors' wishes. Employers will be debarred from influencing their employees' choice of charities, as will the agency. Employers will however be entirely free to decide whether or not to participate in the scheme. If they do, they will be liable to pay a fee of 5% to the agency.

It is envisaged that some charities may act as agencies both for themselves and for others. If they do so they will put themselves at a disadvantage since they will be debarred from promoting their

own cause. It is likely for this reason that most of the agency work will be carried out by organisations such as the Charities Aid Foundation.

Almost all the benefit at present goes either to one national charity, Dr Barnados, or to occupational benefit funds. There is virtually no benefit to other national charities. ASBAH has made efforts, long before the 1986 Budget, to get into this field of fundraising and has failed.

The reasons for the failure are highly relevant. First, the entry to a particular company or organisation must be through management. Very many managements do not wish to be seen to be interfering in what they regard as an essentially private matter for individual employees, which is a very reasonable point of view. Quite a number of managements go further and set out to protect their employees against the importunities of charities.

Managements which do not take quite such a rigid line tend to say that an approach to employees must be with the approval of, or by arrangement with, representative bodies not themselves. However Trades Unions and Staff Associations are also apt to take the line that an employee's charitable donations

are his or her own business.

One way or another, the problems of actually making a case to employees are immense.

Whether or not employees are likely to be impressed by tax concessions of this kind is doubtful, bearing in mind that the most that can be saved is about 56p per week. It may be that this concession will have some influence or it may not. However, to talk, as does the Director of the CAF, as if this was a major breakthrough could be extremely damaging especially when companies are considering donation budgets from their own corporate funds.

It would be wrong to appear too negative about all this but it would also be wrong to talk and act as if an instant bonanza had been presented to charities. Where charities already have access to donors in the latter's work situation these new arrangements could strengthen their approach. Where they have no such access, the difficulties remain as formidable as ever. In my opinion the number of people who will be tempted to give to charity by reason of tax concessions, whereas without these concessions they would not have given, is very small indeed.

### HOLIDAY HELPERS

The Holiday Care Service has recently set up a scheme, called Holiday Helpers, to try and find a suitable helper for people who cannot go on holiday on their own. The aim of the scheme is to try and provide a volunteer capable of meeting an enquirer's particular needs and acting as a helper on holiday.

The suitability and capability of prospective volunteers is assessed and they are introduced to enquirers wanting a helper on holiday. No charge is made for the service. The Holiday Care Service cannot, however, pay any part of the cost of the holiday. Enquirers must bear in mind that the additional cost of accommodation and transport for the helper must be met.

For further details contact: Tim Smith, Holiday Helpers, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW. Tel: 0293 775137.

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## FIVE OAKS ASBAH'S centre, Ilkley, Yorks. HOLIDAY COURSES 1987

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April 15/19	DJ Course
April 26/May 2	Wildlife Course
May 8/10	Walking Weekend
May 15/22	Outdoor Pursuits
May 23/30	Dance and Drama
June 5/7	Pot Holing Weekend
June 12/14	Climbing Weekend
June 19/21	Fishing Weekend
June 22/26	Driving Assessment
June 26/July 1	Driving Course
July 3/10	Outdoor Pursuits
July 10/17	Outdoor Pursuits
July 17/24	Outdoor Pursuits
July 24/31	Outdoor Pursuits
Aug 21/30*	Canoeing Holiday in Scotland*
Aug 30/Sept 5	Computer Course
Sept 6/12	Jewellery and Make-up Course
Sept 13/17	Day Trippers Week
Sept 26/Oct 4	International Fashion Course
Oct 9/11	Mobility Weekend
Oct 16/18	Train Enthusiasts Weekend
Oct 18/24	Clothes-making (parents)
Oct 24/31	Fashion Course
Nov 1/8	Driving Course
Nov 9/13	Driving Assessment
Dec 2/6	DJ Course

There will be a slight increase in price of about 6-7% over 1986:

Week course: £135    4 day: £74  
Weekend: £25    All plus 6-7% increase

Contact: Paul Cooper, Five Oaks, The Drive, Ben Rhydding, Nr Ilkley, West Yorkshire (0943 603013) for details. (If you want help with meeting the cost ASBAH may be able to help.)

\* Subject to confirmation

## ASBAH Appeals Diary

Nov 19/20	Beaujolais Challenge — Finish, Winter Gardens, Margate
Dec 17	'Datasolve' Carol Service — St Peter's, Eaton Square, SW1
Feb 24	Charity Greyhound Meeting — Wimbledon Stadium
April 25	Ripon Race Day
May 9/10	Chatathon — Glaziers Hall, London Bridge
Sept 6/7	Fun Bike Day — Chippenham, Suffolk

More appeals' events in future LINKs. For more details contact Douglas Jack at National ASBAH.

**Spina bifida and hydrocephalus come in different degrees of severity. The two men featured on this page illustrate the point. Both, however, have displayed a remarkable amount of determination in achieving their particular goal.**

ready and yet I was still worried about failing. But as soon as I got there and the starting time approached every worry I had was forgotten and I just got on with the business in hand.

We planned to have one hour of balancing the wheelchair and then five minutes break, so that I could stretch the parts of my body the blood wasn't reaching.

All my food and drink had been paid for by Kasbah and prepared by Rose Starkey, the wife of Alan the publicity man for the Air Cadets who would also benefit from the 'Wheelie'.

Right from the start things went wrong. In the first hour I got cramp in the back of both legs and found it quite difficult to control the wheelchair in the air while my helpers (all belonging to the Air Cadets) tried to stop the cramp. After a while things, I'm glad to say, quietened down.

Many friends, associates of Kasbah, came down to give me moral support. This kept me going, I knew as long as people were coming to see me I wouldn't give up.

One very special friend from work turned up and kept me happy. He made me laugh so much that I had difficulty in controlling the wheelchair. When evening came I had my 'telly', a few friends from the Air Cadets and one close friend called David to keep me company.

After about ten hours I was starting to feel the aches in my back and also the cramp in my legs and arms had decided to appear again.

At about two o'clock in the morning other friends who had been to a party appeared and for a while 'picked me up', when they left we watched some more videos.

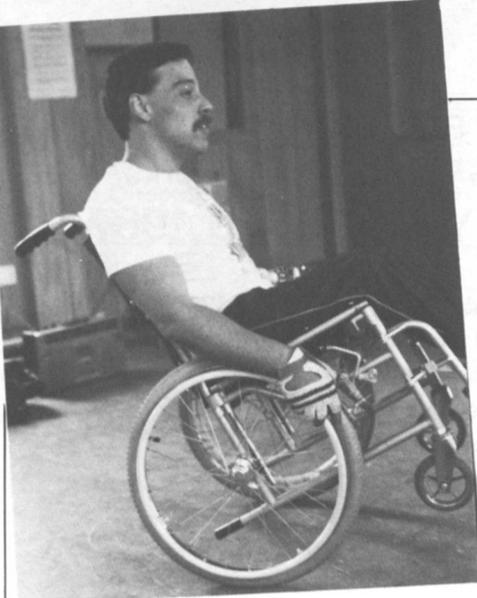
By about five o'clock in the morning not only was I bored but I was in a lot of pain. At one time I felt like giving up.

Finally there was just one hour to go. Then I knew I could do it. What also helped was the fact that Kasbah members came to help me. The last minute was quite funny and I nearly fluffed it.

After the final countdown and the roar of cheers when the time was up it felt really good to know I had achieved a feat like this one.

I had raised £534.80 and a special thank you is due to all who sponsored me and especially the Blue Circle staff at Northfleet who were very generous.

Next — the London Marathon.



**SIMON SMITH**

## Where there's a 'wheelie' there's a way

by Simon Smith

**I** DECIDED on a sponsored 24-hour Wheelchair Wheelie for two reasons. I was fed up doing nothing for Kasbah who have done a lot to help me with my flat and I knew that such an unusual event for charity would bring in a lot of money.

I first mentioned the idea to three people in the Kent local association. Pat Edser, Heather Mcleod and Lynn Atkins all thought I was a raving lunatic to want to try for something like this. At the time I thought it wouldn't be too difficult, but I was to be proved very wrong.

Soon we moved onto getting sponsorship forms printed and luckily I had a friend at work who not only designed the form but also printed it for me.

After the forms were completed I then set about getting the sponsors. I did this by going around Gravesend and into places where I knew there would be a lot of staff employed.

The response was brilliant and people were very kind in wishing me good luck. But they still thought I was mad.

Then came the big day, 5th July, 1986 — Saturday. The venue was my local Air Cadets Base in Wrotham Road, Gravesend.

I was feeling good but a little apprehensive and a bit worried because I had shot my mouth off. I had everything

## Glen's dream comes true



**GLEN ROWE**

"Well, I don't see any reason why you shouldn't join the RAF".

These words had a special ring to them for 22-year-old Glen Rowe. He had been born with spina bifida and hydrocephalus and had already been turned down by the civilian police. Now a specialist was telling him that his wildest dreams would come true.

Glen has now enlisted for 9 years as a gunner in the RAF Regiment.

He says: "When considering my application, the RAF attached great importance to the running that I have been doing regularly since 1980.

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## FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rate: £3.00 for 30 words max; £4.25 for 30-45 words; £5.50 for 45-60 words. Cheque or postal order payable to 'ASBAH'.

Adverts for next LINK (Jan/Feb) should be in by December 15. 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.

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**EXMOUTH Devon.** Fully equipped, self-catering, 2-bedroom bungalow (sleeps 7). Full central heating. Details: Herts and S. Beds Association. J. Harper, 70 Grove Road, Harpenden, Herts. Tel: 05827 69213 (evenings).

**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.

**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.

**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.

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**ANGLESEY.** Bryn Meirion is a small family guest house in beautiful gardens overlooking the sea. It is on the edge of the holiday town of Benllech. A warm welcome awaits disabled and able-bodied guests. All guest rooms and lounge are accessible. A helper/companion is available. Double bedroom; two large family rooms.

Family atmosphere. Bryn Meirion has been opened by Tim and Chris Holland who used to work at a school for the physically handicapped. Details from Mr and Mrs T. Holland, Bryn Meirion, Amlwch Road, Benllech, Anglesey LL76 8SR. Tel: 0248 853118.

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North Brickhill,  
Beds. MK41 7AY

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Gloucs. GL51 7TO  
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Tel: 01-573 5488.

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Hull. HU6 7TX. Tel: Hull 857165.

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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 5245.

## SUNDERLAND

Mrs A Shepherd,  
115 Holborn Road,  
Sunderland.  
Tel: 091 5283568.

## 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,  
Beaminstor, 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.

## NON AFFILIATED ASSOCIATIONS

### Blackpool & Fylde

Mr John Dewhurst,  
62 Edmonton Place,  
Bispham,  
Blackpool.

### Beeston

Mrs S S Goodfellow,  
5 Cyril Avenue, Beeston.

### Cannock & Walsall

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

### Chesterfield

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

### Consett & District

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

### Derby & District

Ms A Hewitt,  
St Merryin, 20 Burley Hill,  
Allestree, Derby.

### East Anglia

Mr P Grantham,  
7 Ash Close, Downham Market,  
Norfolk, PE38 9PS.  
Tel: 0366 382200.

### Gainsborough & District

Mrs M. Hawkes,  
10 Turpin Close,  
Gainsborough, Lincs.  
DN21 1PA

### Iale of Wight

Mr D J S Sprake,  
Springfield, Totton Lane,  
Chale Green, Ventnor, I.O.W.  
Tel: Chale Green 234.

### Lancaster, Morecambe & District

Mrs M Dyson,  
25 Royds Avenue,  
Heysham, Lancs.

### Rochdale

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

### Somerset

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

### Teesside

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

## 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 SY7 9QY.

#### 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.

## NORTHERN IRELAND

Mr J. Rippey,  
Long Eaves,  
24 Tulleywiggan Road,  
Cookstown,  
Co. Tyrone.  
Tel: Cookstown 62290.

## OTHER ASSOCIATIONS

## SCOTTISH SPINA BIFIDA ASSOCIATION

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

## 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.