



# Link

Association for Spina Bifida and Hydrocephalus/ASBAH

May/June 1987

Issue Number 110

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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**

**President: Sir Hugh Rossi, MP**

**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*

**Appeals Director:** Mr Douglas Jack

**Assistant Director Administration:** } Mr Paul Dobson, *BA(Hons), Grad.IPM.*

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**Research/Information Officer:** Miss Pat Corns

**Disabled Living Advisers:** } Miss Mary Barton  
} Mrs Leonie Holgate, *MCSP*  
} Mr Philip Watson

**Link Editor:** Mrs Sue Gearing

**Five Oaks, Ilkley, Yorks**

**Manager:** Miss Joan Pheasant, *NNC*

**Development Officer:** Mr Paul Cooper, *BA(Hons)*

## ASBAH Publications

All available from National Office  
Cheques payable to "ASBAH"

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

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

Spina Bifida & You - A Guide for Young  
People (1985) . . . . . £3.50

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

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

Life & Death-thoughts on  
bereavement (1983) . . . . . 75p

Making our Way-individual experiences of  
young people with spina bifida and/or  
hydrocephalus (1984) . . . . . £1.20

**BOKLETS/ LEAFLETS**

General leaflet . . . . . 13p  
Housing: general advice for young people . . . . . Free  
60p for professionals

**All prices include post and packing**

Five Oaks leaflet . . . . . Free

**FACT SHEETS** . . . . . up to 10 copies free

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into Welsh. Please send at least 30p postage

**VISUAL AIDS**

Slide sets and notes (12 slides) Living with  
Spina Bifida . . . . . £8.62 inc. VAT  
**Video** — Training video  
on Hydrocephalus (May 1987).  
Contact PR dept for details.

**MAGAZINES**

LIFT - for members of young ASBAH (LIFT) . . . . . Free  
Causeway - for contributors to ASBAH's work . . . . . Free

**LINK SUBSCRIPTION**

UK . . . . . £3.30  
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Air Mail . . . . . £10.80

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UK only. Overseas rates on request

*Whilst 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

THROUGHOUT the history of the local associations there have always been some parents who have had the ability and sensitivity to share their experiences with other families. In some local associations this was, and is still being done far more than in others. For new parents of a baby with spina bifida and/or hydrocephalus facing the bewilderment and fear of the future with a disabled child, it can be a great comfort to talk to someone who has been through it all before. Advice and a listening ear are also useful for parents as their child grows into adulthood. Not everyone is able to do this informal 'counselling', and not everyone is willing.

Some associations may have forgotten this unique service which one or two of its members may be able to give. Sometimes National ASBAH hears of a parent, perhaps whose child has grown up or has died, who is very keen to give help either in the form of advice or of a practical nature. Because of the personal nature of such help, it is an offer which National cannot easily accept and make use of. It is at local level where the most good can be made of this kind of help.

### FLORIDA HOLIDAY

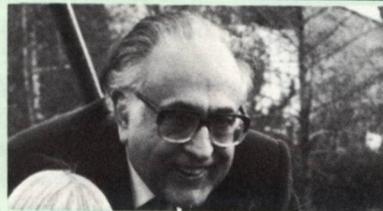
THERE ARE STILL PLACES FOR THE LINK READERS HOLIDAY TO THE USA THIS AUTUMN - See page 7

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## FRONT COVER

Spring is certainly in the air for these two young people -Alan Pearson and Michelle Foreman, who were married at Sunderland Civic Centre on Easter Sunday. Alan, who has rheumatoid arthritis met Michelle, 21, who has spina bifida and hydrocephalus, at one of the social gatherings at Nookside Centre, Sunderland, over a year ago.

Photo: The Echo, Sunderland.

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# 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 12. Send to the Editor at National Office

21 YEARS 1966 - 1987

ASBAH

STILL LOOKING FOR THE KEY



## AN IMPORTANT MILESTONE -

**A MESSAGE FROM MR ROBIN  
MACKENZIE, CHAIRMAN, ASBAH**



Mr Robin Mackenzie

I am sure that all readers of LINK now know that 1987 is ASBAH's 21st birthday year. Until recently 21 was the age at which people were assumed to have reached a certain wisdom and maturity and were ready to launch themselves into the serious business of life. I believe that this is still so, and that even with the official adult age at 18, most people still see 21 as an important milestone in their life.

What is true of a person is also true of an organisation. New organisations have to grow and to learn before they become wise and useful members of their community. At 21 it is assumed one has completed one's initial learning - although learning is a process that never stops - and one is ready to move forward to the adventures and achievements ahead.

ASBAH has reached this important point in its

existence. During the past 21 years, we at ASBAH, have been building up knowledge of what the Association should be doing and learning how to do it. We have achieved a secure base from which we provide a wide range of services to those who have spina bifida and hydrocephalus. We are looked upon as competent, caring and mature and our actions are admired and our opinion sought by a wide range of organisations, including government.

This is our achievement in our first 21 years. Now we must look to the future, for no organisation can afford to stand still. We are trying to insure that the resources available to us keep pace with our needs. We must work to improve the service we give to our own community. Indeed we should not be thinking only of our own community, for we must play our part in ensuring that improved care and facilities are available to all who suffer disability and handicap. It is only by helping other organisations that we can expect from them the advice and assistance, that on so many occasions, prove valuable to us.

As we enter our next 21 years we are preparing plans to increase our field services, not only by moving into new geographic areas but also by improving the services we provide and adding new ones. We are working to increase our training facilities for staff and others and for young adults with spina bifida and hydrocephalus. We plan to increase our support for research and to extend our ability, alone and with others, to campaign for a better deal for all who are disabled.

That is the future, but on our birthday let us not forget the past. We must thank all those who have worked to build up ASBAH, not only nationally but in local associations and groups throughout the country. Without them there would be no ASBAH and without their continuing work there will be no future growth.

We depend on them all - staff, members, and volunteers. I thank you all and wish you a Happy Birthday and continuing success.

## Birthday celebration at the House of Lords

*In the impressive setting of one of the rooms of the House of Lords, a very special gathering for ASBAH took place on April 2 to mark the Association's official 21st birthday.*

*Baroness Masham, one of the Association's Vice Presidents hosted a reception for 120 members and friends of ASBAH. They were founder members, people who have contributed to ASBAH's development in one way or another over the years, and*

*present day staff and committee members.*

*It proved to be a very informal and pleasant way of meeting together to mark this special occasion.*

*Sir Hugh Rossi, ASBAH's new President, was able to attend and to meet many members of 'the ASBAH family', and to be introduced to some of the Founder Members.*

## A WELCOME TO SIR HUGH ROSSI, MP ASBAH'S NEW PRESIDENT

Everyone connected with ASBAH was very sad when our first President, Lord Maybray King died in 1986. He had for many years taken an active interest in our work.

Our thoughts turned to finding a successor. We are now delighted to announce that Sir Hugh Rossi MP has agreed to become ASBAH's new President.

Sir Hugh has very firm links with ASBAH. He was the Minister of State for the Disabled during the International Year of Disabled People, 1981, and has done much to improve facilities and provision for the disabled.

Sir Hugh became a Vice President of ASBAH in 1985, and has been a great help and support to us.

We are grateful for his active interest.

It is significant that Sir Hugh becomes President in 1987. He has a particular concern and interest in housing for young people with disabilities and 1987 will see the start of a major accommodation project at ASBAH's centre, Five Oaks.

Sir Hugh was formally introduced to members at a Reception at the House of Lords on April 2 to mark ASBAH's 21st Birthday.



Sir Hugh with two young people from Trafford and Salford ASBAH at the laying of the foundation stone for the Stepping Stones project in Manchester in November. The 12 flat development is being built by the Manchester Methodist Housing Association. Trafford and Salford ASBAH will be responsible for the management of four wheelchair adapted flats in the complex.

## CONGRATULATIONS FROM PROFESSOR ZACHARY

"I have just received another excellent edition of LINK and in this 21st year of the Association I want to congratulate you and the whole team on the magnificent work that you do.

I call to mind that Sunday in November all those years ago when about 12 people came to our house for a buffet lunch - people from different parts of the country, some parents, some doctors. In their own areas they had been having small meetings away from the clinic where they could discuss the wider problems associated with spina bifida.

On that November day it was agreed to meet the following Spring in Birmingham for the actual launch of ASBAH. In those early days the association was run on a hand to mouth existence, but due to the extremely hard work of those volunteers, the basis was laid for full time staff, leading to the present team - equally hard working.

When I read in LINK about all that is being done in ASBAH it makes me green with envy that I am no longer able to be involved closely, but I take this opportunity of congratulating ASBAH on achieving 21 years and showing no signs of slackening off its efforts for the handicapped - rather the reverse.

My best wishes to you all and continued success under the inspiring leadership of Moyna Gilbertson."

*Robert Zachary*

*A letter from Prof Zachary, a founder member of ASBAH and one of the Vice Presidents, recalls the very early days of the Association. Prof Zachary now lives in Australia.*



Professor Robert Zachary

21 YEARS 1966 - 1987

ASBAH

STILL LOOKING FOR THE KEY



**C**ONGRATULATIONS! on reaching your 21st birthday.  
You were 'in your infancy' early in 1969 when my family made contact with you on my behalf after I had given birth to a son, Richard, who was found to have Spina Bifida and Hydrocephalus. What a frightening and traumatic time it was in the early days, but the advice and reassuring literature forthcoming from ASBAH helped to answer many of the worrying questions confronting us in 1969 . . . . .

Of course, time has passed and many advances have been made in the treatment of SB&H and with the good work of ASBAH the public is a little more aware of the conditions and what they mean, I wouldn't say that since 1969 life has been 'plain sailing'; far from it — having overcome one hurdle, there is always another to take its place!

Since ASBAH has 'come of age' so have many of our 'children' and in consequence many other problems have manifested themselves concerning higher education, employment, independent mobility and independent housing — with ASBAH forever endeavouring to keep abreast of the ever-changing needs of those young people and adults it seeks to represent.

**GOOD LUCK FOR THE FUTURE** and my many thanks and appreciation for your help in the past.  
**PENNY PARFETT**  
East Malling Kent

Happy 21st birthday ASBAH! I was five years old in 1966.  
I was particularly pleased to have the opportunity of attending two of ASBAH's dressmaking courses at Five Oaks, in 1983 and 1984. I am being blind too never thought I'd have the chance of making any clothes for myself. I came home from Five Oaks with a dress and a suit which, with some help from the staff, I made myself.  
I hope I'll have another chance one day to return to Five Oaks as I enjoyed the courses very much.

**L. EDWARDS**  
Pontnewydd  
CWMBRAN, Gwent.

Firstly, Happy Birthday to you all, and may I take this opportunity of thanking you for all the meetings which have been arranged, and also the interesting "speakers" you have given us.

They have not only been very educational but have also helped us with any worries we might have.

We have been able to discuss problems with other parents, and our disabled parties have seen that there are others like themselves.

All in all a very worthwhile cause!

**ALISON LAY**  
Holbrook, Suffolk.

**The Midland Association would like to wish ASBAH many Happy Returns of Twenty-first birthday and success in the future.**

I have a 15-year-old daughter born with Apert's syndrome who developed hydrocephalus when she was 6 months old. We suffered many traumas in the first 7 years associated with her shunt, and received little help or support. Our understanding of hydrocephalus was also minimal.

Our first introduction to ASBAH was accidental when I went along to a support group meeting to tell them about the work of our local toy library. I quickly realised that these people could offer me support. We were welcomed into the group and have made many friends over the years. We have received help and

support from both the field-worker, who has become a family friend, and the group which has since enlarged to become the Suffolk Association.

We have received a lot of information from both speakers and booklets written in layman's language. Our newsletter and 'Link' keep us updated with news and developments and we have a fund of names and addresses for further help.

We have much to thank ASBAH for and our only regret is that we had so many years struggling on our own.

**VAL DURRANT**  
Ipswich

Happy Twenty-First Birthday ASBAH. Congratulations on your 21st birthday and best wishes for the future. May you go from strength to strength.

Committee and members  
**Hull and District ASBAH**

The St Helen's Association would like to send its congratulations and best wishes on ASBAH's 21st birthday.

May you continue with your help for many years to come.

## THE RIGHT TO A HOME - FAMILIES IN CRISIS

•ON APRIL 1, National ASBAH participated in a conference organised by Family Forum as part of the International Year of Shelter for the Homeless -

*The Right to a home-Families in crisis.* It highlighted the effect of inadequate housing and homelessness on both families and family life in the UK.

The two keynote speakers

were Rod Hackney, President Elect of the Royal Institute of British Architects, and Sheila McKechnie, Director of Shelter. In the afternoon workshops were held on the housing needs of different groups of people. Miss Carolyn Smith, ASBAH's Accommodation Officer lead the workshop on housing for people with mental and physical

handicaps. The statement for Government produced by this workshop, called for the Government to recognise the rights of disabled people to housing and the need for more accommodation options; for local authorities to meet the Dept of Environment recommended level of housing suitable for people with disabilities; and for

local authorities to keep records of adapted properties; also for Government to recognise that the provision of housing for the disabled must not be divorced from the provision of other support services.

•100,000 households in the UK are classified as homeless

•An estimated 3% of homeless people have a physical handicap.

### ASBAH's new video on hydrocephalus

Sunday March 15, 1987

"I am sitting in the ASBAH minibus at the moment (8.45 am) hiding from the cold that has turned the rest of the film crew blue. This is our second day of filming in Ilkley and we are based at the Cow and Calf rocks on Ilkley Moor to film some young people on a Five Oaks course as they tackle climbing and abseiling.

"But, to begin at the beginning.... A couple of days after starting work at ASBAH as a Public Relations Officer in January I was made aware of ASBAH's need for a new training video on the subject of hydrocephalus".

*Thanks to the hard work of Mr Duncan Forrest, Dr Roger Bayston and Mrs Leonie Holgate, the script was well on the way to being completed. It needed to be produced and filmed.*

"I had some contacts in the film world, and a few days later, Creative Post

Productions (CPP) in London offered us free production on a half an hour video."

*ASBAH's video on hydrocephalus was really underway!*

"Since then many professional people have offered their services at a reduced rate including director, Simon van der Borgh and cameraman, Philip Grosvenor....

"We have now finished the filming stage and should have a superb quality video which will be available some time this month (May).

"Thanks must go to everyone involved for being so co-operative and generous. It has been hard work, but hopefully it will be worthwhile".

Sam Kirby,  
Public Relations Officer

*More details in the next LINK. Meanwhile if you need information contact the PR Dept at National.*

### LINK FLORIDA HOLIDAY - still time to book!



There has been a magnificent response to this first ever LINK readers' holiday. There will, in fact, be two holidays - one, flying out of Gatwick, (October 3 -- Oct 18), and the other flying direct from Manchester a little later, (Oct 17 - Nov 1).

The tour operator, Panovista, reports that there are vacancies on both departures, so if you are still interested - but thought you had missed the boat (or rather the British Airways flight!) - there is time to find out more and to book. Contact Panovista (address below).

I will be very happy to answer any queries that Panovista can't help you with.

The holiday represents very good value for money. It's a 14 day, two centre holiday based in Orlando and Clearwater, Florida, and the cost includes admission to a number of star attractions in the area, including Disneyworld and the Epcot Centre (3 day pass). The cost for adults is £678 and for children £440. It

does not include food.

An ASBAH representative will be on both holidays to make sure that all goes well, and to help generally, but we do ask that holidaymakers are more-or-less independent and able to cope with their personal needs. For those who have already booked, Panovista will shortly be sending out more information about the holiday, and medical and visa forms.

Panovista can be contacted at: 78 Sea Road, Sunderland, SR6 9DB. Tel:091 5494444.

*Peter Leonard who had spina bifida and lived at Papworth, Cambridgeshire, was really looking forward to the Florida holiday, but sadly he died suddenly at the end of March. Colleagues where he worked at the Electronics Division of Papworth Industries, and friends, made a collection in his memory and have sent £25 to be used as most appropriate on the LINK reader's holiday.*

Sue Gearing, Editor

# Daily Living

THE RANGE of equipment on the market can be very bewildering and often it is difficult and time-consuming to find just what you are looking for.

We invite you to write in and let us know if you need some kind of special equipment or mobility aid. - LINK will then find out what is available and report on it in the next available issue. Also please let us have details about any equipment or items - large or small - that you have tried and tested, and any other handy hints to pass on to other readers.

\*\*\*\*\*

Link has received an enquiry from Mrs Audrey Shepherd, Secretary of Sunderland ASBAH about portable wheelchair lifts that could be used for vehicles or buildings.....



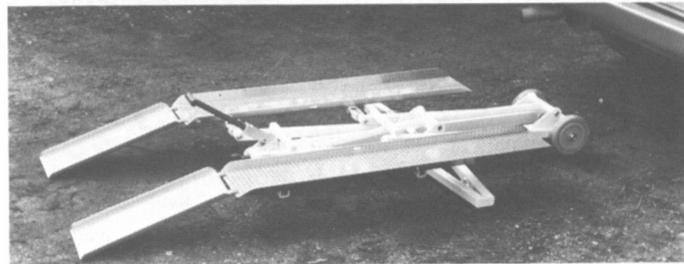
## THE UNWIN QUIKLIFT

..... so Link has been to look at the UNWIN QUIKLIFT, manufactured from a small workshop in the hamlet of Lufton near Yeovil in Somerset.

The Lillywhite family from Chard in Somerset went along with LINK Editor, Sue Gearing, to test the Quiklift. They have two children in wheelchairs - Anne Marie, 16, who has spina bifida, and 13 year old Maria who has cerebral palsy.

The Quiklift is a portable hydraulic lift, not too heavy, and easy to pull along using the handle which also acts as the hydraulic lever. It folds down to a neat 43" x 13" x 11". David Unwin who showed us the lift said "Unlike an electric lift there is nothing mechanical that is likely to break. After an enormous amount of use the seals may wear, but these can be replaced very easily".

To operate, the lift is placed on the ground next to the vehicle entrance, and easily unhooked. Two



Top: Maria on the Quiklift. Above: The lift unfolded, ready for use.

small portable ramplets hook on and then it is ready for the wheelchair and passenger. It is suitable for most sizes of wheelchairs. Mrs Lillywhite was pleased that it could take Maria's chair which has narrowly spaced wheels. It will take wheel widths from 13-25".

Mrs Lillywhite found it very easy to pump up (operated by foot). It will go to a maximum height of 25" which makes it ideal for most ordinary vehicles and minibuses, though it is not high enough for coaches.

"I like the way in which the small ramps lift up once the chair is on to prevent it rolling backwards" said Mrs Lillywhite.

The lift can be stowed away under

seats or the gangway of the minibus.

At the end of the journey the wheelchair rolls easily on to the lift again, and light pressure on the handle lowers the lift very smoothly and easily.

It seems to be surprisingly good value at £360 (plus VAT if applicable).

The Lillywhites felt it could be a really useful buy for a family, or for a local association doing a lot of travel by minibus.

Unwins are demonstrating the lift at exhibitions around the country such as NAIDEX, and it will be at the Mobility Roadshow at Crowthorne in Berkshire, from June 12-14.

*continued on next page*

Unwins entered the field of equipment for the disabled quite by chance when the Red Cross in Yeovil asked if they could design a wheelchair clamp for vehicles. They came up with their highly successful range of clamps, and now also produce seat harnesses, and market a range of building and vehicle ramps. This is a Swedish range called Rampus. "They are good so we decided to import these and sell them over here, and in exchange we export our clamps to them" said Robert Unwin. Exporting to Japan is also becoming lucrative. The Japanese are very keen on the clamps and are now buying the lifts too.

While LINK was at Unwins it was able to see a brand new product, the EASYLOCK.

It is a wheelchair restraint and clamp and also converts into an ordinary passenger seat. It has been designed in particular for community transport and is already being tried out by Dial-a-Rides in Dagenham and Barking, after trials at Middlesex Polytechnic. The Easy lock has clamps which adjust to fit different sizes of chair, and attach to the upright tubes of the chair, so it is clamped firmly against the wheelchair restraint which looks like a conventional car seat back with a headrest. The wheelchair passenger can of course benefit from the headrest if he wishes which gives added safety in the event of an accident. The chair is easily unclamped, either by the passenger or an attendant. What is very useful for community transport schemes which like to be flexible, is that in a matter of seconds the Easylock can be folded down into an ordinary (though slightly narrower than usual) passenger seat.

The price is about £300.

\*\*\*\*\*

For details of all these contact:

C. N. Unwin Ltd., Lufton, Yeovil, Somerset. BA 22 8SZ.

Tel: Yeovil (0935) 75359

**This column is only a guide to some of the equipment on the market. It is not a recommendation for individual items. Please do seek expert advice when going to buy any product, to ensure safety and suitability**

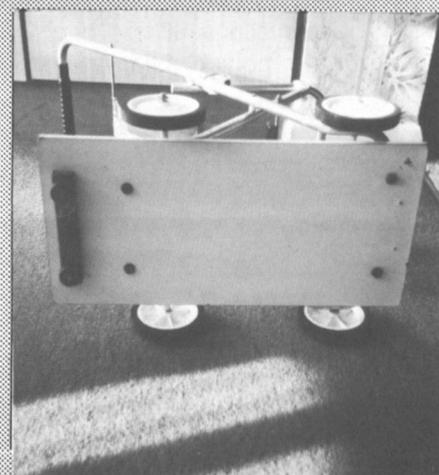


The Easylock, ready for the wheelchair to be clamped in. When not needed for a wheelchair, the back folds down in a couple of seconds to make an ordinary seat.



The Easylock with the wheelchair firmly in position. The passenger has the benefit of the headrest.

## Daily Living



Two views of the pushchair adapted by Stephen Walsh for his daughter, Caroline.

He decided to solve for himself the problem of how to get his daughter to walk in full calipers, when the walking frame she was using would not go in the direction she wanted.

His design which stabilises the chair will allow Caroline to walk in the direction she chooses.

"It will allow her to transport her dollies wherever she wants, and if she wants to stop, the pushchair will stop when her weight is applied on the handrail. The pushchair was made to be easily demountable to fit inside a suitcase for our holidays."

Mr Walsh will be pleased to answer any queries about the adaptation. His address is Home Farm, Kemnal Road, Chislehurst, Kent BR7 6LY. Tel: 01-468 7767

continued on next page

## Daily Living

### Mobility-and communication-with the Elva Twin

Anthea Jones, 18, on the **Elva Twin** purchased from the Children in Need Appeal and as a result of the fund-raising activity of her friends at King Henry VIII School, Abergavenny.

"It has proved to be a marvellous means of communication between her and the other children at the school. It isn't like a wheelchair. The children are fascinated by it, and think it's marvellous. It has been a good talking point", said Anthea's mother.

The Elva goes at a fair speed - a fast walk- and will climb ordinary kerbs. Having the twin wheels it is very stable. "That's why we chose it



rather than the single wheeler. It's also more powerful" said Mrs Jones.

Anthea uses it every day at school to get up the steep ramps. The school is built on a slope so the land lends itself to the siting of ramps outside so that all three floors are accessible.

Mrs Jones said that the repairs and after sales service had proved to be very good. The first Elva Twin they

had gave some trouble. Mrs Jones telephoned the manufacturer and in a short space of time they had supplied a new vehicle which has proved very satisfactory.

The Twin Elva cost £1,585.

For details contact *Electric Leisure Vehicles Ltd., 17 St George Industrial Estate, Frimley Road, Camberley, Surrey GU15 2QW*

## PLUMBING SERVICES FOR THE DISABLED COMMUNITY

This independent consulting group was set up by Stephen Walsh with the object of improving the quality of life of disabled people.

Mr Walsh, a Chartered Engineer and Plumbing Engineer, was motivated to set up the service after being involved with the day to day care of his spina bifida daughter, Caroline, now aged 11.

After successfully designing and gaining permission for a downstairs toilet for Caroline's use, Mr Walsh became increasingly aware that there were many aids and designs to help the disabled maintain self-respect. He also realised that he had an added bonus - an insight - gained from the experience of bringing up Caroline and helping to meet her needs. "I became aware that because of an interest I had acquired a great deal of information and expertise in designing and adapting homes to make life easier for the disabled".

So Mr Walsh formed the new service to offer disabled people the benefit of his knowledge.

If you have a plumbing, heating, building accommodation or access problem contact Plumbing Services who may be able to help. Fees are negotiable.

If you wish to contact Mr Walsh his address is on the previous page (see the article about the adapted pushchair).

## Let your Disabled Child ride a PONY

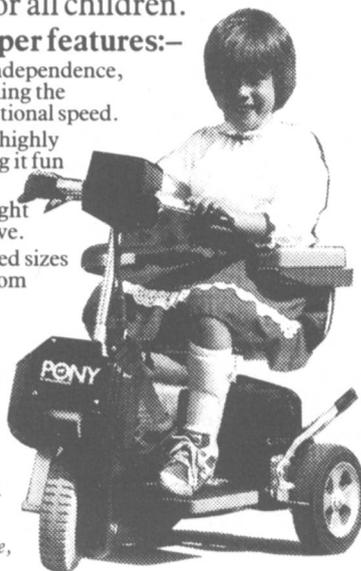
Unique, portable 3 wheeler (can be stowed in the boot of a car). Designed for the disabled child, but is fun for all children.

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  
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Name \_\_\_\_\_

Address \_\_\_\_\_

# Letters

## Adult clinics - the question of funding

I was very interested to read the article *Growing Concern* (Link Jan/Feb) and concur with all the points which it made. We are still running our "young adult clinics" in the Newcastle area - but the clinics have been running on a weekly basis for 3-4 years. This had to be done to cope with the increasing number of referrals.

One of our problems at the moment is the question of funding. The clinic is a regional one (as is our spina bifida children's clinic) but the regions are very reluctant to pay for these services, and we may be paid to act only in an advisory capacity to those living outside the Newcastle area. One can only hope!

**Jean Robson, MB, BS**

Associate Specialist in Orthopaedic Surgery.  
Freeman Hospital,  
Newcastle upon Tyne

**Editor's note:** *The clinic run by the Sussex ASBAH at Chailey Hospital came up against the same problem of funding, with some of the six Area Health Authorities covered by the clinic refusing to pay for people to go there. After campaigning and enlisting the help of MPs and other people of influence Sussex Association was finally able to get the clinic 'adopted' by all six Health Authorities who now pay for those who attend the clinic from their particular area.*

*Let us hope that the Newcastle Clinic is able to get the same understanding and co-operation from its Health Authorities so that this very valuable service for young adults is able to continue.*

## The correct use of language

I was interested to read the article on the Campaign for Real People in the March/April Link which includes a section on language, but I was dismayed to see on the opposite page of LINK in "Letters" that you refer to a *disabled lift* and a *disabled toilet*. (Letter from the Museum Curator at Bath)

As a responsible lift manufacturer we wholeheartedly endorse the correct use of language when referring to people with disabilities and we would not expect products such as ours to be referred to as *disabled lifts*, but rather as *lifts for disabled people*.

An indication of our concern with language is demonstrated by our sponsorship of the booklet *Providing for Disabled Visitors*. It would have been so easy to entitle this book *Providing for the Disabled* but it would have been entirely inappropriate and, therefore, we were very pleased to see that the English Tourist Board and the Holiday Care Service chose what we regard as the "correct" title, and in line with this we scheduled the sponsorship of the booklet to form part of our special programme for helping disabled people.

**A.N.R. Stannah,**

Director, Stannah Lifts,  
Andover, Hants.

## A special morning

Is it really 21 years since ASBAH started? My, how time does fly.

I was reminded, reading your Birthday issue of LINK, that in the mid-sixties I was running a pre-school playgroup at Pyrford, near Woking, Surrey, with three friends, Ann Moore, Brenda Keats and Olive Preston.

We used the village hall, and although we were just 'mums', we had been officially blessed by the local authorities. We were all very flattered when Miss D. Hodges, playgroup projects director approached us and asked us

whether we would consider taking a spina bifida child into our group.

We knew absolutely nothing about the condition, or even about handicapped children generally, so it was arranged that we should all attend the new pre-school playgroup in Woking that was specifically for handicapped toddlers.

We helped at it for several weeks before it was arranged that our new 'customer' would join us.

Miss Hodges came on the first day with mother and her young daughter - an attractive five year old with gorgeous curly hair. We were filled with trepidation as the time came when mum left and Miss Hodges left and we were trusted to cope on our own.

Imagine our horror when we saw young Fiona take her under her wing - a true leader, Fiona - and start hauling her up onto the climbing frame in preparation for going down the slide! But Miss Hodges had told us to watch surreptitiously and try to let things happen naturally...was this letting things happen naturally we wondered, or should we intervene?

Lisa's degree of handicap was not too bad, but she needed calipers to give her mobility.

Fiona eventually got her to the top of the slide, with much yanking and pushing from willing helpers, and Lisa set off groundwards under her own steam, with beaming smile all over her face.

Her mother, when she heard, was delighted; needless to say it was not the last time that Lisa used the slide.

**What happened to Lisa?**

I wonder what happened to Lisa? She was expected to undergo several operations in the future to increase her mobility, and at that time it was not known how much could be achieved.

The four of us moved on to various careers after our own children grew up. But I think that to each of us the memory of that morning when Lisa was hauled up to the top of the climbing frame by Fiona was 'special'.

**Mrs Jane Pearce,**

News Editor,  
Woking News & Mail,  
Surrey.

# DISABILITY INCOME -

## Time for change

Ian McMaster of Disability Alliance looks at the case for a comprehensive disability income scheme

For the past two years, organisations of and for people with disabilities have been defending the existing social security system against the attacks of the 'Fowler Reviews' and the Government's 'Reform of Social Security'. Much time and effort has been spent arguing that the Government's proposals will lead to considerable hardship for people with disabilities - particularly those whose disabilities are more severe.

### Out of the frying pan....

This defence of the existing system has not come from a belief that the system is either adequate or fair. It is simply that the Government's proposals are worse! At the moment, the system of Supplementary Benefit additional weekly payments for items such as heating, diet, clothing, laundry, and domestic assistance, allows some degree of flexibility and response to individual need. The Government intends to remove this in April 1988 by replacing supplementary benefit with a new 'Income Support' which is based on inadequate flat rate premiums for certain groups of people, including those defined as 'sick or disabled'.

Along with cuts in Housing Benefit, maternity benefits, and the State Earnings Related Pension Scheme (SERPS), the abolition of Supplementary Benefit and its various weekly additions will intensify the poverty and hardship already experienced by a very large number of people with disabilities.

### The need to resist

Although the Social Security Act 1986 gave the Government the power to introduce all its proposals, it is still essential that they are resisted as vigorously as possible. This is because most of the proposals will not be implemented

until April 1988. Even more important - in what will almost certainly be an election year - is that attention should be given to developing acceptable and adequate alternatives to the existing system. We have been defending a system which we do not believe in: it is time now to present the alternatives.

This is precisely what the Disability Alliance has been doing over the past year. Alongside our campaigning against the Social Security Bill, we have been revising and updating our proposals for a comprehensive Disability Income scheme for all people with disabilities.

### A decade of pressure

The Disability Alliance was set up in 1974 in response to a Government White Paper - 'Social Security Provision for Chronically Sick and Disabled People'. This came after a decade of pressure, following the formation of the Disablement Income Group, for an income scheme designed to meet the problems of poverty and inadequate incomes faced by many people with disabilities in the UK.

The 1974 White Paper announced a package of measures costing just £23m per year. At the time this was equivalent to just 34p per disabled person per week. Organisations of and for people with disabilities were 'united in fury' at the poverty of this package and the Disability Alliance was formed. Originally the Alliance had 30 member organisations. It now has over 90 including ASBAH. In 1975 the Disability Alliance set out the case for a comprehensive Disability Income scheme for people with disabilities. This policy statement - 'Poverty and Disability' - identified the three principal financial problems faced by people with disabilities as:

- poverty
- lower incomes generally than non-disabled people
- the inequitable treatment of different groups of people with disabilities.

The Alliance argued that all people with disabilities should have a right to income on equal terms. No distinction should be made on the basis of the cause or type of disability - i.e. whether it is a mental or physical disability, congenital or acquired, or whether it arises from an accident at home, at work, or whilst on war service. Instead, we argued that there should be a benefit which varies only with the severity of the person's disability. This would help to overcome the various costs and restrictions which the disability places on the person's lifestyle. On top of this, we argued that people with disabilities who could not work should receive an adequate 'income maintenance' benefit which meant that they did not have to rely on means-tested benefits, such as Supplementary Benefit.

### Piecemeal changes

Over the past decade, all the major political parties have accepted the case for a comprehensive disability income scheme. But there has been little progress in practice. Instead, there has been a series of piecemeal changes, such as the introduction of Mobility Allowance and Non-Contributory Invalidity Pension (Severe Disablement Allowance). Although some of these changes have been beneficial, they have not removed the long-standing anomalies in provision for people with disabilities. Indeed, in recent years, a number of vital benefits such as Sickness and Invalidity

*Continued on next page*

## DISABILITY INCOME CONTINUED

Benefit have been cut. In other areas, including Attendance Allowance, Mobility Allowance and Severe Disablement Allowance, new anomalies have been created.

### The need for a comprehensive scheme

The case for a comprehensive Disability Income scheme is therefore even stronger today than in the mid 1970s. Such a scheme is needed to provide adequate incomes for people with disabilities and to eliminate the anomalies in the treatment of people with equally severe disablement.

It is well established that people with disabilities require higher incomes than the non-disabled because of the direct and indirect costs of their disability. Yet people with disabilities still have very restricted access to employment, and therefore earnings.

A large proportion of people with disabilities therefore rely on Social Security benefits for part or all of their income. Yet these benefits are completely inadequate. Some two-thirds of people with disabilities are now living in or on the margins of poverty—defined as having an income of up to 40% more than the current supplementary benefit rates. This is a far higher proportion than for the non-disabled population.

Furthermore, among people with the severest disabilities, there can be a difference in entitlement to non means-tested benefits of as much as £150 per week. At one extreme are people whose disability has arisen from an industrial or war injury, for whom there is an elaborate (although still often inadequate) system of weekly allowances. At the other extreme are people who are unable to work and who have an insufficient national insurance record to qualify for the contributory invalidity benefit.

People with disabilities have a fundamental right to an income to meet the extra costs of their disability, and also to an income to

meet normal living expenses if they are unable to work. Of course, income alone is not sufficient to ensure full participation in society. There are many other changes which need to be made in the areas of employment, access, transport, housing, social services, education and public attitudes. However, provision of adequate incomes as of right is essential to eliminate poverty and financial hardship and to enable people with disabilities to participate fully in all aspects of modern day life.

### What Disability Alliance proposes

The Disability Alliance is calling for the introduction of a scheme consisting of:

- *A Disablement Allowance payable to all people with disabilities, regardless of whether they are working or not. The allowance would be paid at one of five rates, varying with the severity of disability*

- *A Disablement Pension payable to all people who are unable to work because of their disability. A reduced pension would be payable to people who are partially capable of work.*

- *Provision of adequate benefits for carers of people with disabilities.*

This scheme would replace the existing inadequate and discriminatory system of benefits. All parts of the scheme would be non means-tested and non-contributory. In addition, the Disablement Allowance would be disregarded for the purposes of calculating entitlement to means-tested benefits.

The comprehensive nature of the scheme means that it would meet the needs of people with disabilities who are currently excluded altogether from benefits or who are treated inequitably by the existing system. These groups

include elderly people with disabilities, children with disabilities, married women, people with mental handicaps, people with chronic mental illness, people with visual and communication handicaps, and people with a variety of specific disabilities such as epilepsy, multiple sclerosis and diabetes.

### Time for action

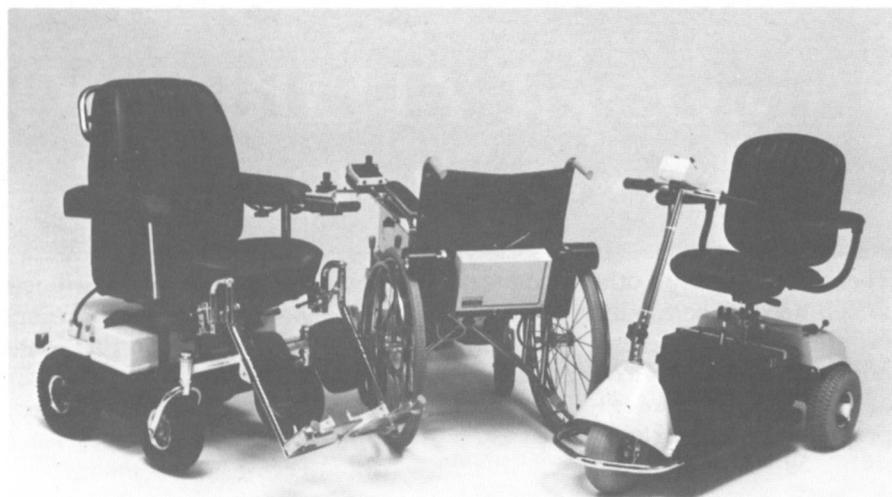
The expenditure necessary for such a scheme will undoubtedly be considerable. But various surveys of public opinion have shown that people support such a scheme, even if it means higher taxes.

The Disability Alliance will be publishing its revised policy document in the near future, and will be launching a major campaign to put the case for a comprehensive Disability Income scheme to be put back on the public and political agendas. The Disability Alliance believes that it is time for 20 years of political commitment to be put into practice, to ensure that the needs of people with disabilities are adequately met. The country can afford a comprehensive Disability Income scheme, and people with disabilities cannot afford to wait any longer.

*Copies of a free summary of the document, fact sheets on poverty and disability, and information about the campaign can be obtained from:*  
**The Disability Alliance,  
5 Denmark Street,  
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# FITTING FASHION

Right: Some of the attractive, reasonably priced and fashion clothes produced by Fashion for the Disabled in Liverpool. The workshop, set up three years ago, is run by Jackie Cocklin who has experience of the fashion trade, and it aims to give disabled people who have problems in buying ordinary off-the-peg clothes the chance to look fashionable. Many of the machinists at the workshop are disabled, employed by MSC. As a result, garments can be made at very competitive prices. A new Boutique range of off-the-peg garments specially designed for disabled people has recently been brought out. All the clothes are available by mail order.

If you would like more details contact Jackie Cooklin, Tudor House, Langshaw Lees, Wood Lane, Netherley, Liverpool L27 4YA.



## BARRY'S LIVELY LIVER BIRDS

Barry Manilow fans on Merseyside have a busy programme of fund raising ahead, and its in aid of ASBAH.

Barry's Liver Birds Club although only small has already held a party, bingo, raffles and auctions and one member's husband was sponsored in the Mersey Marathon. ASBAH has benefited to the tune

of £150. ASBAH is the chosen charity because one of the member's daughters - 18 year old Paulette Fazakerly - has hydrocephalus. "For obvious reasons my daughter is delighted that the club has chosen ASBAH" writes her mother, Mrs Norma Fazakerley, "We have numerous fund raising activities in the pipeline".

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# Are hospitals hospitable?

Mrs Sue Ripley writes about the experiences of her son David who has hydrocephalus. Mrs Ripley is a member of the Hydrocephalus Support Group and also a former Chairman of the National Association for the Welfare of Children in Hospital (NAWCH).

DAVID, our eldest child, was born in 1971. The day before his birth I went to the ante-natal clinic and after an X-ray was told that the baby probably had hydrocephalus. Although this was a great shock and caused us distress, we were grateful that we were not kept in the dark.

David was born by Caesarian section the next day. He looked normal and his head was not abnormally large. The next few days were very tense as each day David's head was measured. By about the fourth day it was apparent that his head was growing faster than was usual for his age. It was agreed that he should be admitted to the local children's hospital immediately after we had both been discharged from the maternity hospital. We were fortunate to be told (by a very sympathetic paediatrician) about David's condition and that I would be able to stay at the hospital with him.

We were equally fortunate in the staff that we met at the children's hospital. Once again the tests and operation were explained to us. We were reassured to see a baby in the adjacent cubicle who had already had the shunt operation. What we did find distressing, however, was the suggestion that if we had not already done so, we should have David baptised - we felt that this meant there was a substantial risk in the operation and that David might die.

The implications of David's condition were not clearly spelt out during our stay in hospital or at

subsequent clinic visits. It was probably not appropriate to tell us about all the possible complications at the time of the first operation, but as David got older and we began to be concerned about him, we found ourselves being told every so often: "Oh, didn't you know, children with hydrocephalus sometimes/often may have squints or fits or development problems or are clumsy". Some indication of possible 'complications' would have been helpful when the immediate anxiety of the shunt operation was over.

Until David was about four we did not meet any other parents of a child with handicaps. It was relief to meet another parent with a handicapped child of a similar age and to be able to 'compare notes' and exchange ideas and suggestions.

David has had about seven short admissions to hospital for a variety of operations (most of them not directly connected with the hydrocephalus) as well as countless clinic visits in his 14 plus years. His handicaps are not as great as other children's and are often not as noticeable - perhaps because of this fact, the treatment he has received has been of variable quality. Some staff don't know how to treat him and either ignore or over-emphasise his difficulties.

Facilities in hospital do not always seem geared to children with handicaps (or children without, either!) Meals are not always appropriate to the child's needs; once there were no teaspoons on the ward, so David had to eat with a dessertspoon. Another of David's difficulties was that he



David and his sister Wendy

was not dry at night until quite a lot older than other children. on several occasions I had to ask for nappies for him at night.

Perhaps the 'nursing process' might have helped, but would a nurse actually ask whether an older child was dry at night?

A parent whose child is more severely handicapped than David told me that her daughter had been ignored in hospital. Not one nurse talked to her although they talked to the other babies and children on the ward! Other parents have said that they felt it necessary to be on the ward at all times, not even leaving for meals, because they felt that the staff could not cope with their child. Is this a common experience? Obviously, staff in training have the same difficulties as anyone else in encountering a child with a handicap for the first time, but what is being done to help them to nurse these children appropriately? Ordinary acute wards are the right place for these children. They have as much right to be there as any other child. I remember being horrified to hear of one authority where a special ward had been opened which segregated children with handicaps from others. The whole subject of children (and adults?) with handicaps receiving (or not receiving) acute care, needs to be studied in more detail.

Sue Ripley

LINK visits Irene Dillnott who believes in . . .

## Making the best of what you have

**F**OR those people lucky enough to be born with a fighting spirit, the hardships of life can be overcome, and even turned to advantage. Necessity can be the mother of invention, and a person who has certainly proved this is Mrs Irene Dillnott who lives in Brighton.

Now aged 64, Irene is a smart, vivacious person, still very much involved in life, and hoping for at least another 20 years: "I'll need this to see a lot of very many things I still haven't seen." This is despite the fact that she was born with spina bifida, and is now confined to a wheelchair.

Born into a working-class family, Irene's handicap was quietly accepted and she had to get on with making the best of it. She had no special care or equipment, no toys save those she made herself, and worst of all, no formal education. "Cripples weren't seen to be educable in those days."

But Irene was determined to teach herself to read and write, and persuaded her father — who was a painter and decorator — to make her some writing books out of rolls of wallpaper. In order to practise her writing skills, she joined a pen club. Before she sent off a letter, her father would spend several hours correcting her writing and spelling. This was the start, and over the years she has used books to acquire knowledge on a wide variety of subjects, and has harnessed her writing ability to campaign on many different fronts (often successfully) not only for her own advantage but to help people suffering in other ways.

Irene has tried all her life to look good and minimise her handicaps. It was a particularly hard job in days gone by when there were no proper incontinence aids, or specialist advice. For instance, she had to make do for years with inefficient, unglamorous and cumbersome home-made rubber pants.

What she can't get she makes or invents . . . like the leg bags which she designed herself . . . Irene explains:

"They are called Post-Op drainage bags and are made for me specially by the Aldon factory, after I wrote to say that conventional bags were too small. (They have to be emptied every half

hour which is not practical when you are out for an afternoon.) I sent them my design and they make them up to my personal requirements. They are not available on prescription, but are sent to my local chemist. They hold 2,000 mls in a special soft kind of plastic. With each bag I get two pieces of ribbon which I tie to my knickers. I have made two thick garters to go round my leg to take the weight, and the bag tucks up underneath to hold down the tap and stop it sticking out. They have given me so much more freedom."

*If anyone wants details of these bags Irene will gladly forward any letters to the factory.*

Another example of her ingenuity is her footwear. "My doctor would only order boots — no shoes — for me. He said I would only walk out of them, as I have no feeling in my feet, so when I had a new pair I used to cut off the tops and make a collar for them. The doctor always admired them, not realising he had ordered them."

Irene dyes her boots: "I have at the moment four pairs — one green, one blue and one red, and have just received a pale grey pair. In the past, I have painted flowers, coloured lines, blobs and things to match whatever dress I was wearing."

Her battles through life have been fought on many different fronts. She struggled from an early age to find some kind of work, whether it was babysitting, doing home jobs, struggling to cope with factory work, or running a transport cafe. Her first husband died after a short period of marriage, and in order to get a second one after her family had grown up — she put an advertisement in the paper — and it worked! She has been a foster mother to many children, and has adopted a son, Paul who is 22 and is a postman and special policeman in his spare time. She also has a daughter of her own aged 32. She lives with her mother and is at present a mature student at Sussex University, studying librarianship.

"My life on the whole has been a very happy one, apart from hospital visits



Irene Dillnott.

and being parted from my family. I have had lots of fun despite the many drawbacks. Most of the fun has been made by one of my sisters. We both got along so well, neither of us had much, but made the most of the little we had. Once or twice a year she and I used to collect about 10 to 15 poor children (sometimes mums and dads too) and take them all camping. My three-wheeled chair, or as things improved — my car, were all the transport we had between us. I used to carry all the tents, blankets, clothes and a box of food, and on top of all this I hid two or three children or babies inside . . . my own being only a few months old. Sometimes it would rain for a week, but no one ever got ill! How I never became poisoned through my pressure sores, I shall never know. Many times I have changed dressings and found grass or straw stuck to them. In fact, I shall never know how I ever managed any of this.

"I have visited many different places since my second husband died five years ago. My daughter has helped me to see the paintings in the National Gallery, the Tussaud wax models, many of the London museums and parks, cathedrals, abbeys, the Barbican Centre, the Tower (where our wheelchair puncture was repaired by a Beefeater!) and the London Dungeons. I saw the final of the ladies' Wimbledon Tennis Championships in 1985. I also go to several of the Promenade Concerts each year."

If any LINK readers would like to know more about the Aldon bag, or dyeing and painting shoes, or have any other queries, Irene will be glad to help if you get in touch with her. The address is: 208 Wild Park Close, Bates Estate, Brighton, East Sussex, BN2 4HG. Tel: 0273 693327.



# England's World Cup winners put on their football boots again -for ASBAH!

The England World Cup winning team of 1966 will be back in action on Sunday July 26 at Valley Parade, Bradford, the ground of the Bradford City Football Club. Their opponents will be the first team to beat them after they won the World Cup - which happened to be Scotland.

The match will be played for the benefit of ASBAH, which started life that same year -1966!

It should prove to be an enjoyable celebration during ASBAH's

21st birthday year - and it should also raise some much needed funds.

Not all the players from the original team will be available, and some of those that are able to play may not be at peak fitness. However, ASBAH hopes that most of them will make a token appearance and be substituted as the match progresses...if necessary after five or ten minutes! A pool of thirty players, all internationals, will be present and ready to take part.

The company which provided the gear for the World Cup Final has promised to do so again, and it will be an exact replica.

We also hope that ASBAH's old friend Kenneth Wolstenholme will agree to give the commentary.

Many details remain to be settled and these will be announced as soon as possible. So watch the next LINK or ring ASBAH Appeals Department for more information.



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Training, a job, a house, a kitten and  
a sporting grant...it all happened in

## Just one year

BY PAM SCOTT, AN EXECUTIVE OFFICER AT  
HM LAND REGISTRY IN DURHAM. PAM WHO  
IS 31, HAS SPINA BIFIDA AND IS IN A  
WHEELCHAIR. PAM HAS AN HND IN APPLIED  
BIOLOGY AND A DEGREE IN MICROBIOLOGY.

After leaving college in 1980 I was unemployed for three years and then employed as an accounts clerk in an estate agents from April 1983. Although the job was very interesting it was poorly paid and offered no promotion whatsoever.

In March 1985 I had an interview at the Land Registry in Durham and was delighted to learn that I was to join them in September as a direct entrant EO. Since then I have been through a training course on the first stages of the work, and am now well established and happy in a legal group, looking forward to a new training course on a different aspect of the work.

When I joined the Land Registry I had been on the council housing list for over two years. In that time I had been offered only two flats with coal fires and an 'aged persons' bungalow - totally unsuitable for someone in a wheelchair.

*The Land Registry were very helpful and*

Kew in the country

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Pam receives her training grant from Jimmy Saville

*approached the local council and a local housing association on Pam's behalf...*

...the result being that on May 28, 1986, I moved into a newly built, adapted, two bedroom bungalow five miles from the office. I was able to decorate my new home to my taste and I added the final touch by adopting a six week old kitten called Pepsi. We are both very content there!

I am also very involved in sporting activities and have competed in the Great North Run. I came second in the female wheelchair race and won a £400 training grant presented by Jimmy Saville, which will be used towards my own racing wheelchair. I have also taken part, with my work colleagues, in a Sport Aid Run where together we ran 242 miles.

As I write I see an interesting summer ahead - I am going to an international youth camp in Germany for 14 days, arranged through a colleague from the office.

Who would have thought, 12 months ago, that all this would have happened!

### DERBYSHIRE MOBILITY OPEN DAY

A Mobility Open Day is being run by a big garage in Derbyshire, - Smiths of Ilkeston, - on Sunday June 21, 10am - 5pm.

A free invitation is extended to any disabled person who is interested. Advice will be available on methods of obtaining a new car including hire purchase or lease, using the Mobility Allowance.

There will be a chance to try out a Vauxhall Astra Automatic specially adapted with varying controls for different disabilities. A driving instructor who specialises in teaching disabled learners will be there for the test drives and to offer help and advice. It will also be possible to book a test drive for a later date. There will be a full range of Vauxhall cars, and a range of hand controls and aids to driving. Light refreshments will be available.

Smiths of Ilkeston have made special efforts to advise disabled people wishing to get cars of their own. They hope there will be a good response to this Open Day. For details telephone Smiths on Ilkeston (0602) 322387.

## Personal Toilet on Long Flights from the Disabled Living Foundation Information Service.

FOR MANY disabled people — particularly those who are continent but have mobility problems — long flights are not easy. This booklet points out that “none of the suggestions are entirely satisfactory, but with careful planning and practice before the flight, many people will learn to cope adequately”.

The list of contents will show the scope of the booklet: Use of cabin toilet (design of compartment and aisle wheelchair); Alternative methods (body worn appliances, urinals, temporary catheterisation, protective garments, medication, restricted intake before flight); Cleanliness and smell; Defecation; Organisations; Reading lists. **Any readers going on the LINK holiday to Florida are strongly recommended to send for a copy of this useful publication.**

Available from DLF, 380/384 Harrow Road, London W9 2HU. Tel: 01-289 6111.

## Care in the Air

from the Air Transport Users Committee.

THIS USEFUL booklet of advice for handicapped travellers is now in its 4th

## Spectator's Access Guide for disabled people

compiled by Peter Lawton

PETER LAWTON has updated the popular RADAR access guide to Sports and Leisure to produce this new 368 page guide. It consists of regional sections divided into sporting headings such as cricket, horse racing, league football, motor racing and swimming. There is also a 'special national centres' heading covering indoor athletics, rowing, show jumping and tennis. Over 250 venues are mentioned. Essential information for the disabled spectator is listed — parking, access to toilets, viewing facilities.

Price £3 (including p and p) from the publishers: RADAR, 25 Mortimer Street, London W1N 8AB.

## Understanding Disability

by Victoria Stopford

FOR anyone involved with social or health care work this will prove a useful handbook. It gives basic information about a wide range of physical and mental handicaps and is easy to digest and to cross-reference.

Price £5.50. Published by Edward Arnold, 41 Bedford Square, London WC1B 3DQ.

# Reading Matter

edition. It contains advice on how to minimise difficulties en route, and what to expect by way of assistance and special help.

A copy of *Care in the Air* is being sent to everyone going on the LINK readers' holiday to Florida.



Airport access?

## Sixteen and Then What?

The future for mentally  
impaired adults

by Andrina E McCormack.

FOR PARENTS of older children with mental handicaps this could prove a useful basis for discussion as well as a source of information. Chapters deal with issues such as Family feelings, It helps to talk, a Life after School, Feeling worthwhile. There is also practical information about who is there to help, and where to set about finding accommodation. Useful addresses of organisations overseas are given, too.

Price £5.25. Published by Helena Press, Orchard Lane, Goathland, Whitby, N. Yorks YO22 5JT.

## REMAP Yearbook

published by RADAR

REMAP (Rehabilitations Engineering Movement Advisory Panels) which is 20 years old, now has 90 panels throughout England, Scotland and Wales. This free service gives disabled people the services of skilled engineers who try to come up with a piece of equipment or an aid, tailor-made to suit the individual's needs. If you would like to find out more about REMAP, this book would be a good start.

It gives local addresses and lists some

of the equipment produced so far by the different REMAP panels, from such things as a wheelchair anti-reversing lock, or a gadget to enable someone in a wheelchair to play skittles (the Bristol panel, of course!), to a device for a one-armed bagpiper!

If you have a problem which you think might possibly be solved with a little skilled engineering, why not get in touch with your nearest REMAP.

Price of book £2. From RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400.

## Employer's Guide to Disability from RADAR (The Royal Association for Disability and Rehabilitation)

DEMAND for RADAR's first Employer's Guide was so high that a second edition has now been produced and the opportunity has been taken to revise and expand it extensively. Unlike the first edition, the Guide is now bought and an updating service won't be available.

The Guide aims to help employers realise what disabled people can do rather than what they cannot do. By describing a variety of disabilities in non-medical terms it challenges popular misconceptions and distinguishes between disability and handicap. It is handicap rather than disability which creates problems and throughout the book emphasis is placed on how handicaps associated with particular disabilities can be minimised.

Details are provided on the nature of some 30 disabilities. The implications for employment, health and safety and sources of further specific information are given. The chapters which follow deal with wider issues connected with disability and include information on statutory services, legislation, access and safety, and the importance of a formal employment policy. Information is also given about available grants and practical aids. The book concludes with case studies of employment problems and how these are solved.

Price £17.95. Published by Woodhead-Faulkner. Available from bookshops, or from RADAR (address above) at £19 to include postage.

## Guides to Information

from GLAD (Greater London  
Association for Disabled  
People).

THE FIRST two in this new series of information leaflets for disabled people deal with Transport and Holidays. They are a guide to useful sources of information, and to publications and organisations.

Available free (please send s.a.e.) from GLAD, 336 Brixton Road, London SW9 7AA. Tel: 01-274 0107.

*Interlink Directory of Services for families and their young children with special needs.*

by the Under-Fives Project at MENCAP in London.

THE DIRECTORY is designed to help professionals direct parents of very young children with special needs — particularly with learning disabilities — towards the right support. Part I gives information on each London Borough, which vary so much although the same framework is used for all. Part II provides general information. Ideally the Directory should be complemented by a localised borough guide with more detail, and in some boroughs these do exist. Information about services outside the area are also given. This should facilitate cross referrals and help families moving from one area to another.

Thanks to funding by the London Boroughs Disability Resource Team, the Directory is available free of charge.

Available from MENCAP Interlink, 115 Golden Lane, EC1Y 0TJ. Tel: 01-250 4105.

### *How to Push a Wheelchair*

by David Griffiths and David Wynne.

THIS USEFUL advice, first printed on a small duplicator by the two Davids to give to helpers and friends, proved so popular that the 7th edition has just been published and is now in booklet form supported by advertising.

It gives tips, with sketches, both for wheelchair attendants and those who push their chairs themselves, covering kerbs, rough ground and transferring from chair to car seat or toilet. There is also a section on choosing a suitable chair.

Price 50p each from *The Disabled Motorists Club, Unit 2a, Atcham Estate, Upton Magna, Shrewsbury SY4 4UG. Tel: 074 377 489. (Special rates for orders of five or more.)*

## Reading Matter

### REVIEW *WHEELCHAIRS and their use*

A guide to choosing a wheelchair by Janet Weyers, in association with Bert Massie of RADAR.

THIS excellent book is set out in two sections:

*Section One* includes chapters on the types of chairs and special features available; where to get help and advice; how and where chairs can be obtained and funded. Two important chapters cover insurance and maintenance.

*Section Two* sets out to describe in detail, with charts and descriptions a range of more than 400 individual chairs and ranges of wheelchairs. It is a guide for selection to enable individual users to choose a wheelchair that will suit their own needs and lifestyle. It is in the use of Section Two that wheelchair users may need the help of people described in Chapter Three (Section I).

The guide quite rightly does not set out to recommend particular wheelchairs; it gives details of where each chair is available: whether it be on free loan from DHSS, or from manufacturer to buy or hire.

The check lists are very helpful, as are the charts which give comparisons of similar chairs.

The introduction to the book indicates that choosing the right wheelchair is often more complicated than people realise, and that it is easy to make an expensive mistake. It has been



common for most disabled people to accept what they are provided with from ALAC. There has been very little information that describes what is available, and from where, and this is the first guide of its type.

It covers the subject in great detail and is well set out. Much work and a lot of research has gone into its production. However, I do have some reservations that many of our young members would find the amount of concentration needed to use such a guide would prohibit its use. They would need some help from a professional or more experienced person.

As a professional I appreciate not only the text of the book, but also the very appropriate advertising within it.

**Mrs Jean Black,**  
Chairman of Trafford & Salford ASBAH, and a Disabled Living Adviser for Trafford Social Services.

Price £3 to include postage from RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400.

## Dutch magazine for happy holidays in Europe

A DUTCH organisation, Vakantie En Handicap, offering a range of services for disabled holidaymakers, has now produced a magazine (translated in English, German and French) with useful information for carefree holidays in Europe.

This includes:

- A databank of wheelchair accessible accommodation.
- An adapted bus service from the Netherlands via Maastricht and Dijon to the South of France, where it is then available for excursions to Monte Carlo and Cannes.
- A choice of wheelchair accessible accommodation — hotels, apartments, campsites and cottages.
- An accessible hotel in Spain.
- The introduction of an assistance service in Torremolinos.
- An adapted camper that can even accommodate electric wheelchairs, available for hire on a self-drive basis.
- A 'Kip' caravan adapted for wheelchair users.



Available from: Stichting Vakantie en Handicap, Oldenoert 102, 9351 KS Leek, Netherlands.



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# Advertising

## FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rates: £3 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 the next LINK (July/Aug) should be in by  
June 12. 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, Whithurch, Shropshire. Tel: Whitchurch 3691

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

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

**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

**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, Bransgore, Christchurch, Dorset. Tel: 0425 72055.

**MABLETHORPE, Lincs.** Well equipped chalet. Sleeps 6. Two bedrooms. Fully adapted for wheelchairs. Fitted with automatic washing machine. On holiday site with facilities. A few minutes from town centre. Easy wheelchair access to beach. From £85 per week inclusive. Details: Jean Lupton, 36 Arran Drive, Horsforth, Leeds, LS18 5SW. Tel: 532 587654, evenings.

**PRESTATYN, North Wales.** Large chalet type caravan. Sleeps 6. Two bedrooms, bathroom, toilet. Fully equipped. Suitable for wheelchair users who live independently, or families. From £85 per week, inclusive. Details: Jean Lupton, 36 Arran Drive, Horsforth, Leeds, LS18 5SW. Tel: 532 587654.

**RYE HARBOUR, Sussex.** Fully equipped mobile home, adapted for wheelchair users. Sleeps 4. Clubhouse on site. Details: Mr P Borthwick, 170 Hollington Old Lane, St Leonards, E.Sussex. Tel: 0424 51145.

**SELSEY, Sussex.** Purpose built 7 berth mobile home, fully adapted for wheelchair users. Cot available. Licensed site. Details: Mrs M. Holmes, 11 Grove Road, Ashted, Surrey KT21 1BE. Tel: Asht. (03722) 76730.

**SELSEY, Sussex.** Six berth purpose built fully equipped mobile home. Ramp access. Site near sea. Pool, club, etc. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton SO2 9LT. Tel: 0703 444921.

**WESTWARD HO, North Devon.** Holiday Bungalow. Sleeps 6. Excellent beach. S.a.e. to : Mr G.L.Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: Wolv. 751484.

**WINTERTON ON SEA, Nr Great Yarmouth.** Chalet bungalow. Sleeps 6. 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. Morris. Tel: 0494 32184.

### EXCHANGE AND MART

**Malden Rally Special Go Kart.** Excellent Condition. New batteries. For Sale: £400. Tel: 01 590 9355.

**BEC Electric Scooter.** Very good condition. Little use. Approx 4 years old. Offers in the first instant to: Mrs Poole, 123 Gerrards Green, Beaminster, Dorset, DT8 3EA, or tel: 0308 862614 eves.

**Nissan Micra GL Auto.** Dec 1983. Silver. Three door. Hand controls. 8,500 miles. Excellent condition. For sale: £3,600. New MOT. Tel: Brighton (0273) 563260.

**Meyra Electric Wheelchair.** Model 3422. Lights, indicators. Good condition. Climbs kerbs. Waterproofs and spare charger included. £950. Tel: 049 161 2867.

### WANTED

Members for a PHAB-style choir - *The Gallery Singers*. Based at The Neighbourhood Centre, 44 Sydenham Rd., Sydenham, London SE26. Meets 2nd and 4th Wednes. of each month. 7.30-9.30 pm. Transport provided for those who live in the Borough of Lewisham. Also required: a pianist who can read sheet music. Everyone, disabled or able-bodied, is welcome. Age immaterial. Details: Mrs Margaret Parker-Smith, Tel: 698 0323 (eves); Mrs Beatrice Pusey, Tel: 697 5936. Miss Jane Salter, Tel: 639 4006 (eves).

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