Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

Jan/Feb 85

Happy New Year from members of the new local association in South Wales. See page 5.

Year of Youth themes:

Jobs Code:

Fashion for the Disabled:

Hydrocephalus:

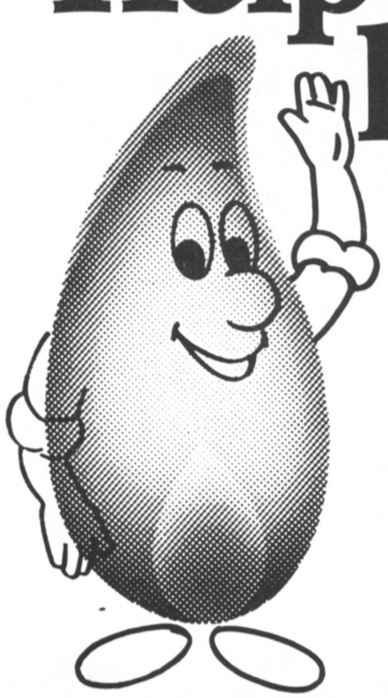
Problems in older children;

Study Day;

a self-help group?

LINK 96

“Help yourself to the help you need.”



British Gas offers a wide range of help to those who need it most—elderly and disabled people. If you have a disability—or have friends or relatives in need of help—here are some of the ways in which we can make life easier for you.

COOKING

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

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

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

GAS FIRES

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

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

CENTRAL HEATING

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

PAYING FOR GAS

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

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

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

HOW TO HELP YOURSELF

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

MORE HELP

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

BRITISH GAS

Link 96

Association for Spina Bifida and Hydrocephalus/ASBAH

Correspondence to ASBAH at the
National Office:
22 Upper Woburn Place,
London WC1H 0EP
Registered Charity No. 249338
Tel: 01-388 1382/5

Patron:
HRH The Duchess of Gloucester

Chairman: Mr D M Bryant

Hon Treasurer: Mr R H Smith

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

Executive Director:
Miss M P Gilbertson, MCSP, FBIM

Finance Director:
Mr Derek Knightbridge, FCCA

Appeals Director:
Miss Judy Kay, MIPR

Services Director:
Mrs B Newman

Administrator:
Paul Dobson, BA (Hons)

Disabled Living Advisers:
Miss Mary Barton, MCSP
Miss Andrea Robinson, RGN, SCM, HV
Miss Mary Small, Dip OT, SROT

Fieldwork Co-ordinator:
Mrs T Cole, MICA

Accommodation & Development Officer:
Ms Siobhan Rowe, BA, Dip HA

Project Leader at Five Oaks, Ilkley, Yorks.
(Tel: 0943 609468):
Mr Jim Stanton

Information Officer:
Miss B Holland

Link Editor:
Mrs Susan Gearing

LIFT (Young ASBAH) Organisers:
Paul Cooper, BA (Hons)
Vivian Harper, BSc

THE INTERNATIONAL Year of Youth (IYY) — it's a peculiar way to describe 1985. It is also an acknowledgement of the problems facing the youth of today.

Probably a young generation has never before to face such turbulent times of change. I know the young people of 40-50 years ago faced war and unemployment but I still do not think they faced anything like the peace time stresses of today's young people.

The key to why I think that the youth of today is under more pressure than other young generations lies in their "expectations".

Let's take the World for example. It's a much smaller place — relatively speaking — than 50 years ago. The USA is six hours away and a return plane ticket costs just over £200.

Just look at the Pop World. Some young people are "promoted" to superstar. Videos make it easier to enjoy these fantasies on a mass scale. The problems arise when the video stops and the drudgery of day to day life starts. Supplementary benefit might give one the superstar life style for an hour.

To sum up attitudes towards life in general, the exclusive adult club of the past is being whittled away in young people's minds. It's no longer, "I'm not old enough". It's "I want to have a go", and this is where the crunch comes. Most adults still have the attitudes of the past — "You're not old enough". As a consequence many young people find themselves confused and frustrated.

Ask yourself one question. "Were you concerned with world peace at 14?" YES/NO . . . Young people are today! SS 20's and Cruise missiles are hardly ever out of the news and believe me they frighten young people.

I have deliberately painted a bleak picture of two of the three themes of the International Year of Youth — Peace and Participation. Young people want to participate but it is difficult in an adult dominated world. They want world peace but at the moment this issue is out of their hands.

Which brings me to the third theme of IYY — Development. The whole developmental process of a generation is at stake. When a political system is thriving allegiances are made which carry the system through its bad times.

However, young people today seem to be facing permanent bad times. Three million unemployed may be five million in years to come. If this is so then the political system we live in will not have allies. Young people will not have seen "the good times". This could lead to instability and a threat to our democratic way of life.

We do not want this to happen and thus IYY, with its themes of Peace, Participation and Development, has got to be a starting place for a democratic future. The pillar that democracy is built on is Participation — not just for a year and then about-face. IYY and its committees must keep replenishing themselves from young people.

In short, we need Peace so that people can Participate and, in turn, Develop. That development can then help sustain Peace, and so on.

The three themes go hand in hand. I wait with baited breath.

PAUL COOPER
LIFT Organiser

CONTENTS

Mobility Road Show returns this year

FOLLOWING the success of the 1983 Mobility Road Show , staged by the Department of Transport, it has been decided to hold a show every other year.

This year's Show will be on June 13/15 at the Transport and Road Research Laboratory. The purpose is to give disabled people the chance to find out whether they are likely to have the basic capacity to drive, and to discover the kind of car and modifications that would suit their needs.

The Road Research Laboratory is at Crowthorne, Berkshire. For more details ring them on Crowthorne 0344 773131.

Car assessments take to the road

CAR ADAPTION assessments are being carried out in different parts of the country over the next three years by Banstead Place Mobility Centre, thanks to a grant from the Ford Motor Company.

A fully adapted Ford Escort and assessment equipment, together with a therapist and driving consultant are travelling to Bath/Bristol—January; Belfast—February; York—March; Chester—April and to other venues yet to be confirmed.

The assessments, costing £30, are designed to help any disabled person who wishes to learn to drive, or who already drives and wishes to change vehicles. Assessments will be by appointment only. For more details contact: Banstead Place, Mobility Centre, Park Road, Banstead, Surrey SM7 3EE. Tel: Burgh Heath 5164.

ANYONE in Wales can be assessed *free* on the simulator at Briadene, Cardiff. Tel: Nell Edwards 0222 591284. The Mobility Information Service, based in Telford, Shropshire has a simulator for assessments. The cost is £10 each. The simulator will visit you if several assessments are required in one area. Tel: David Griffiths 0952 507653.

Competition

A computer challenge for IYY

COULD YOU invent some kind of input device to help severely disabled people to use a computer?

If you think you can and you are aged 15-18 why not have a go and enter the Disablement Income Group's competition (closing date April 1) as part of the activities of International Year of Youth.

Someone with severely restricted movement can use a microcomputer through voice controlled input, for example, or a head-worn light pen. It makes it possible to perform tasks and reach goals that would not have otherwise been possible.

The competition winner will receive the 1985 Megan Du Boisson Award, and an ICL personal computer for his school. There are also cash prizes. The competition is sponsored by ICL.

For more information contact: Ms Pauline Thompson, DIG Charitable Trust, Atlee House, Toynbee Hall, 28 Commercial Street, London E1 6LR. Tel: 01-247 2128.

Harding Award for Lady Hamilton

THE HARDING Award, presented annually for 'outstanding work of immediate or future benefit to disabled people' has been awarded to Lady Hamilton, CBE, MA.

Lady Hamilton is perhaps best known for her work as Chairman of the Disabled Living Foundation. She has done much to spread the concept of aids demonstration centres and information services.

Disabled Drivers

THE correct address of the Disabled Drivers' Motor Club (mentioned in the last LINK) is: 1a Dudley Gardens, Ealing, London W13 9LU. Tel: 01-840 1515.

We apologise for the error.

Front Cover:

New group to be based in Dyfed

THE FRONT COVER picture shows a group of mothers and children enjoying themselves at the Stackpole Trust Cottages* in Pembrokeshire. The mothers are setting up a local association for those with spina bifida and hydrocephalus and their families living in the scattered communities of West Wales.

Over 40 parents and children came together for a special week at Stackpole to discuss their problems and hopes for the future.

The new local association is to be based in Dyfed. For more information contact ASBAH Councillor, Mrs Linda Tuckey, Goldboro Far Hundleton, Dyfed.

*Stackpole is a comfortable beautifully converted holiday centr for disabled people, families and friends set in a beautiful part of the Pembrokeshire coast.

For more details contact: Mrs A M S Jones, Reaches Riant, Lawrenny, Kilgetty, Dyfed.

Photo: Western Telegraph.

ASBAH Course at Castle Priory

'SOCIAL & Educational Needs of Young People with Spina Bifida and/or Hydrocephalus' is the subject of a four-day residential course being run by ASBAH at the Spastics Society College, Castle Priory in Oxfordshire, Thursday February 7-Sunday February 10.

The course is aimed particularly at teachers in ordinary schools where they have pupils with spina bifida and or hydrocephalus, and at members of the medical professional. Parents are welcome.

Subjects covered will include medical aspects of spina bifida and of hydrocephalus, independence training, mobility, curriculum planning, accommodation, etc.

The cost is approx. £94. For details of day rates and for booking forms and any other information contact: Castle Priory College, Thames Street, Wallingford, Oxon. OX10 0HE. Tel: Wallingford 37551.

It's the second course of its kind run by ASBAH.

New Code on Employment is first in Europe

A VOLUNTARY Code of Practice on the Employment of Disabled People has been launched by the Manpower Services Commission. It is a positive step to try and persuade employers that employing disabled people can be a practical proposition and to their advantage.

It was drawn up at the request of the Government with advice from a wide range of interests including disability organisations, such as ASBAH. It is the first document of its kind on this subject to be published in this country or in Europe. Chairmen of leading companies have been urged to encourage use of the Code by their managers, and the MSC's locally based Disablement Advisory Service teams are promoting the Code as part of their developing work of education and persuasion with employers. Observance of the Code is voluntary but hopefully it will be widely adopted by all types of employers in both the public and private sectors.

The first part of the Code outlines important policy considerations for senior management with regard to employing, training and retraining disabled people so that they receive their proper share of opportunities. It also reminds management of the legal obligations of companies.

Part two of the Code is for day-to-day use by personnel managers and describes good practices — many of which are observed by leading employers — and gives guidance on how to implement them. These include:

- Guidance on safety at work and standards of health and attendance.
- Guidance on recruitment and selection procedures and ways of increasing the number of disabled applicants applying for jobs.
- Suggestions on how to integrate disabled people into the workforce.

  Details the help available such as alterations to premises and equipment and the provision of special aids.
- Gives details of the Quota system which continues to be in operation.

There is a strong lobby that maintains that a Code of Practice unsupported by legislation will be ignored. But As the law in this respect — the Quota system — has proved ineffective, this new move is an attempt at reasoned argument and persuasion.

There will be no improvement of the employment situation for disabled people until employers realise that disability does not mean inability, and that taking on a disabled employee can be a sound business proposition.

There are many examples such as the food-canning factory which could not keep its employees for long because of the boring, very repetitive work. The solution was to recruit mentally retarded people from a nearby adult training centre. These workers did not see the tasks as repetitive and their capabilities were used to the full.

From many studies of the performance of disabled people, the message is that they have fewer accidents than their non-disabled counterparts, have less absence from work, and are at least as productive.

The actual number of disabled people who are unemployed is not known. The official statistics suggest nearly 85,000, but there are a great many more who have not bothered to register for employment, often because they have been discouraged from doing so because of the poor prospects of finding work.

In 1983 only one Government department — the Royal Mint — met its 3% Quota, according to a pamplet* published by the Low Pay Unit and Disability Alliance. Neither the Department of Employment nor the DHSS met their Quotas. No county council, only one London borough and one in ten metropolitan district councils met their Quota requirements last year.

Employers who feel unable to comply with the Quota may be issued with a permit relieving them of this duty. Both the number of permits, and the number of employers without a permit but who are illegally below the Quota have risen. Enforcement of the law is extremely rare — only 10 prosecutions in the last 40 years.

Permits are issued as the MSC admits 'as a matter of routine . . . a twice yearly exercise which has only a minimal impact on their policies and practices'.

If you would like copies of the Code of Practice — either for yourself or for local employers, they are available free from: Room W1030, Manpower Services Commission, Moorfoot, Sheffield S1 4PQ.

*"A Right to Work: Disability and Employment", price £2.35 from The Low Pay Unit, 9 Poland Street, London W1V 3DG. (01-437 1780).

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

Some long-term sick and disabled people will now be able to claim a new benefit if they are unable to work and don't qualify for Sickness or Invalidity Benefit.

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

SDA replaces Non-Contributory Invalidity Pension (NCIP) and Housewives' Non-Contributory Invalidity Pension (HNCIP). Everyone who used to receive NCIP or HNCIP will have been transferred to SDA automatically.

One of the main differences between SDA and the previous benefits is that married women will be able to claim SDA even if they are able to carry out normal household duties.

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

People aged 50 or over and those aged 16 to 34 can get SDA now.

Those aged 35 to 49 cannot get SDA until November 1985 but may still be able to claim NCIP or HNCIP if they met the conditions before November 29th, 1984.

Pick up a copy of the SDA leaflet at your local social security office or fill in the coupon below and send it to DHSS Leaflets Unit, P.O. Box 21, Stanmore, Middlesex HA7 1AY.

Please send me the explanatory leaflet and claim form for:
Severe Disablement Allowance ☐ NCIP ☐ HNCIP ☐ Tick the one (s) you want.
(Please allow 21 days for delivery.)

Name____________________

Address____________________

____________________ Postcode__________

Issued by the Department of Health and Social Security.

Members of Tyneside basket ball team who won the Slipad Trophy for Basketball during the Junior Games at Stoke Mandeville last year. All are pupils from the Pendower Hall School in Newcastle upon Tyne. As well as the trophy, presented by Peaudouce the manufacturers of Slipad, the winning team received special pens and sweatshirts. Tyneside won in a close match against the Notts. Panthers from Nottingham. The games were the 4th annual event of their kind organised by the British Paraplegic Sports Society for disabled junior athletes.

Holiday hope

A GROUP of mentally handicapped adults living at the Western Care Centre in Co Mayo in the Irish Republic, is interested in organising an exchange holiday this year with a group of mentally or physically handicapped people and staff of a residential home somewhere outside Southern Ireland. The number of people involved could be as few as four plus staff.

For more information contact: Ms Helen Ryden, Western Care Centre, Barrack Hill, Newport, Co Mayo, Irish Republic. Tel: 098 41193.

"Please would you do up my shoelace and tie up my friend's bow properly!" Young Jodie Rothwell, and 'friend' at the nursery for spina bifida and other physically handicapped children at Tudor House, Netherley, Liverpool.

Copy date for the next issue is February 10

Eight young people from Hull and District Association who completed a 26 mile marathon to boost their association's holiday funds. They completed it in five hours, 40 minutes 23 seconds and raised £1,000. Photo: Hull Daily Mail.

New scheme opens up City centre

CARDIFF Shopmobility is a scheme, started recently in the City centre, to provide electrically powered wheelchairs, scooters and manual wheelchairs for people who have limited mobility. The aim is to help them to shop and use the other facilities in the centre.

Mrs Brenda Sharp, Secretary of South Wales ASBAH writes: "It might be of interest to people visiting this area, or be an idea that other areas might like to think about setting up. Cardiff is particularly suitable for disabled people now as there is a large pedestrianised area in the City centre and also the new St David's Centre precinct."

People wanting a chair can ring in advance to make sure one is available, and at the Shopmobility Centre they are asked to complete a simple form for insurance purposes. There is a test area so that you can get the hang of the chair or scooter before setting out on your own.

The number to ring to book a chair is Cardiff (0222) 399355.

AID for motorists

ASSISTANCE and Independence for Disabled People — AID — is a commercial undertaking that helps disabled people and their families to buy new or used cars at a discount.

The AID staff include disabled people with a knowledge of the cars and equipment now available. In conjunction with the Driving Instructors' Association, AID has a nationwide network of instructors to cope with individual requirements.

See the advertisement on page 5.

Feature

Coping with twins: Where there's a wheelchair there's a way

CONSIDER the less obvious uses of a wheelchair — the large wheels come in handy for hide-and-seek, and the footrest makes a good seat for joyrides round the house.

At least two very young people have already discovered some of the good points about having a 'wheelchair parent'. They are twins, Gemma and Jodie Parkinson, 18-month-old daughters of Philip and Jackie. Mum is the one in the wheelchair because of spina bifida.

LINK readers may remember that we announced the birth of the twins in June 1983. They weighed in at 3lbs 10ozs and 3lbs 12 ozs, and were pictured on the cover of the Sept/Oct 1983 issue when Jackie and Philip were just starting on the long, tiring business of looking after them.

In October LINK went along to visit them in their new home — a council flat on the site of the old Greenwich barracks in South London. It's a good-looking, medium-sized council development, but the drawback as far as Jackie and Philip are concerned are the hills in this historic area of London. This, unfortunately, prevents Jackie from going out on her own in her chair.

However, the new flat has meant a real improvement in their lives. They had to wait about 18 months for it to be completed, and meanwhile just had to make the best of a one bedroom flat which with two growing babies was less than ideal.

They love the size and sunny aspect of their new home, and when LINK visited, Jackie's father was outside paving their small garden to make it into a safe and dry play area for Gemma and Jodie.

Philip and Jackie like the new neighbours, and the twins were already playing with the little girl next door, just a couple of months older than themselves.

Gemma and Jodie were not yet fully mobile. Gemma, the more advanced of the two, had developed her own style of crawling and was getting around all over the place. She looked as though she might take her first step any day. Jodie was crawling a little.

Jackie was still able to ferry both girls around on her wheelchair and hopes that by the time they get too big for this they will be walking.

Philip suffers from epilepsy and isn't in employment. The two of them have built up a good working partnership to deal with their daughters. He's the main shopper and is also adept at coping with all the family chores from nappy changing to cooking. The health visitor comes in to see them every two or three weeks.

Both Philip and Jackie admit that the past 18 months have been hectic, but feel that the situation is getting a little easier as the girls become more independent, and in particular as mealtimes become more normal. To begin with it was taking them about two hours to feed the babies, which didn't leave much time for anything else.

Gemma is the most outgoing of the twins, while Jodie still needs mum's protection when a new visitor comes, like LINK. She certainly boasts a good pair of lungs!

The twins, shortly after their birth

The two are very close, and indeed, this interdependence manifested itself right from the word go. Gemma was allowed home first, leaving Jodie in hospital for an extra couple of days, thus giving Philip and Jackie a chance to cope with one at home first. However, neither twin would settle and more or less cried non stop until Jodie came home too and they were back in tandem.

The support of family and friends has been invaluable. It took three days to celebrate the twins' first birthday because of the number of visitors who came bearing cards and gifts.

Because of the terrain, getting anywhere in the area is a major problem for the family. Jackie is keeping her fingers crossed that they will soon be able to get a car. Help with adaptations has already been offered by the Sidcup Twins Club to which Jodie and Gemma belong.

Jackie has an old invacar which is adequate for her but isn't any good for a family, and after an assessment at Banstead Place Mobility Centre, she was told that she would be able to cope with driving an ordinary adapted car.

An adapted car would mean a great change for them. For most outings, at present, and for shopping trips in which Jackie wishes to participate, they use the Greenwich Dial-a-Ride scheme. It's marvellous, but so popular that they have to book well ahead — even as much as a fortnight for a shopping trip.

But with over 500 customers on the scheme's book, this waiting list isn't surprising.

This year will prove a very lively one for Philip and Jackie as the girls find their feet. It's just as well that there are two parents at home all the time to cope with two of everything!

Chester's £2,500 Knockout

Chester and District Association is £2,500 better off thanks to a round of 'It's A Knockout' competitions. A cheque was presented to the Association by Group Captain David Saunders, the Station Commander at R.A.F. Sealand. It was received by Miss Joanne Eaton. R.A.F. Sealand have been Chester's main sponsor since 1972. This time, with them, in the 'It's A Knockout' competitions were Chester night clubs Rendesvous, Angels, Monroes, Cinderella Rockefellas, King Kab Taxis and Broughton Super Saints F.C.

In the photograph: (standing) l. to r. — J. Bradley, T. Wilson, K. Pollard, M. Smith, Group Captain Saunders, C. Randles, G. Cossins, S. Williams, M. McArron and A. Brown: (front row) J. McMaster, chairman of Chester Association, Joanne Eaton and Clive Laurence, the organiser.

Publications: Advice on offer

'After 16 — What Next?!.

Published by the Family Fund, this is a general guide to the opportunities available to young people with disabilities as they reach 16.

It includes information on education and educational awards and grants, training, work, alternatives to work, benefits and allowances, aids, help with house adaptations, holiday services, independent living, help with becoming mobile and many other services. It is intended for parents, careers advisers, professionals and young people themselves.

Price £1.75 (including p & p) from the National Bureau for Handicapped Students, 40 Brunswick Square, London WC1N 1AZ. Tel: 01-278 3459.

Access in London

This new publication fills a major gap in the provision of access information, and will be of value to disabled visitors and to disabled Londoners. Its contents include getting around London, accommodation, historic buildings, theatres, museums, sports venues and out of town places to visit. Price £2.25 from bookshops. Published by Nicholsons. Also available from RADAR (address above) — £2.80 (to include p & p.)

'The Noo Loo Guide.'

The 3rd Edition of Access to Public Conveniences covers all local authority areas in England. It lists facilities provided by the authorities and a range of other organisations. Price £2 (including p & p) from: RADAR, 25 Mortimer Street, London W1N 8AB.

ASBAH plays host to people from many countries

PLANS are forging ahead for the Third Conference of the International Federation for Hydrocephalus and Spina Bifida. It will take place at the University of Manchester Institute of Science and Technology from 25th to 28th September 1985.

The price for the Conference will be £150 (inclusive of VAT). This will include board and lodging and the Conference attendance fee.

ASBAH is now working towards finalising the programme and will publish this as soon as the organisers have heard from all the speakers.

Topics which it is intended to cover include the problems of the new born, problems associated with growing up, medical matters, such as spinal fusion and also topics such as education, employment, travel, sport, fashion, mobility and 'controlling our own destiny'.

It is hoped that this will make a very useful and informative Conference. However, there will also be a lighter side and the organisers are working on a social programme which will include an excursion, exhibitions and demonstrations, a disco, a sing-a-long bar evening and the official Conference Dinner.

ASBAH hope that many of you will come along to Manchester in September and, in this International Year of Youth, a high proportion of young delegates would be particularly welcome.

LINK will carry further details and there will be an application form in the next issue.


SPEEDWELL
SUPAKART

Letter

IF YOU'VE EVER thought of flying but had doubts about it, here's a letter worth reading from Mrs Maureen Butt of Bedminster Down, Bristol:

Mrs Maureen Butt and daughter Karen at Nigara Falls.

Flying — easier than you think

"Now that we are into a New Year, many of us will be thinking of planning holidays. I would like to say to any of you who would like to go abroad but who are worried about how you would be able to cope, go ahead.

"When you have decided where you would like to holiday, go to the travel agency and explain your special needs — the fact that you will need help at the airports, wheelchair assistance, front seats in the plane, etc. If our experience with British Airways is anything to go by, your needs will be met with great efficiency and without any fuss.

"We have taken our 21 year old daughter, Karen to Spain and recently to Canada. From the time we arrived at the airport to leaving the airport for our destination, the staff were most kind and helpful. Karen felt very at ease and was able to enjoy the thrill and experience of being able to go abroad.

'All I can say is don't be put off. Go and enjoy yourselves. I am sure you will be pleasantly surprised how easy it is".

BOOK REVIEWS

Some advice on smoothing the way

UNDER REVIEW, are two booklets, *Help?!* and *Help Europe?!*. The first line in *Help?!* is "What is the purpose of exchanges?". The answer given — to give young people an international experience. The booklet then advises "Why not examine that simple statement before going on?"

Why not? — experiences international or otherwise can be bad as well as good!

Thus, I think the purpose of the book is set to make sure international exchanges run as smoothly as possible and thus make them "good" experiences.

I think the booklet easily fulfills the purpose set out for it — in my opinion. It sets the scene by saying that exchanges are not just about travelling — they are about meeting people and sharing in their culture.

The advice ranges from group size (about 20 to a leader — the size I was thinking of) to liaison about your exchange programme with your partner group. Do not just expect your partner group to follow your programme — they may have wanted to do something you have not included. The very sensible and simple advice included in the booklet is ask your partner group what they would like to do — then they will ask you.

The Help Europe?! booklet, I will talk about briefly. It gives in depth information about the Countries of Europe — ranging from the emergency (police, ambulance, fire service) phone numbers to the age at which you can buy alcohol. The booklet is a must once you have chosen your European venue. I do not know if a booklet of this kind is to be produced about the USA — I hope so!

Everything is dealt with by the two booklets, even down to "The disabled international phrasebook" which covers words such as caliper and wheelchair — at a glance.

I will not level a criticism at the booklets, but I will point out a danger. The booklets are so good that they almost cut out the experience of learning "by your mistakes".

I think this is a valid point to make linked to the field of disability because, without wanting to generalize, a lot of disabled people lead sheltered lives and are not allowed to "make mistakes". Everything runs so smoothly *for* them. To offset this danger any group planning an exchange visit must work as a team, so everyone involved learns why things are running as they are.

It's not just a holiday — it's an experience — as the booklets point out.

They are £3.50 each, available from the Central Bureau for Educational Visits and Exchanges, Seymour Mews House, Seymour Mews, London W1. Tel: 01-486 5101. New editions are due out any day now.

PAUL COOPER, LIFT ORGANISER

HOLIDAY HINTS

Specialist help and advise on offer

THRESHOLD TRAVEL aim to take the worry out of holidays for disabled people and their families.

Over the past four years they have become the largest tour operator in the UK specialising in the needs of the disabled traveller.

Their 1985 brochure contains tried and tested holiday favourites and exciting new destinations.

For a copy write to: Threshold Travel, Wrendal House, 2 Whitworth Street West, Manchester M1 5WX. Tel: 061 236 9763.

* * * *

RENDEZVOUS is an organisation that arranges trips, mini breaks and holidays for groups of disabled, and elderly people. The outings include coastal excursions, mystery tours, shopping excursions, parties, day trips to France. and holidays in the Quantocks in Somerset, and near Lowestoft. Rendezvous has a specialised fleet of vehicles which groups of disabled people can hire, and will also arrange other outings.

For more information contact:
Rendezvous, 33b High Street,
Bushey, Herts. Tel: 01-950 2976.

FOR MOST disabled people the chance to go and have a garment specially designed and made for them — for only the cost of the materials — is just a pipe dream. But in Liverpool, thanks to Liverpool ASBAH, Marks and Spencer and the Manpower Services Commission, it is a dream that has come true.

Made-to-measure service reaches heights of fashion

IN THE workroom of Merseyside Fashion for the Disabled a strange looking pair of canvas jeans is taking shape — albeit a rather odd shape.

They would certainly never be seen on the racks of a High Street boutique, but nevertheless they will look great when worn by their intended owner — a young man with spina bifida. When he puts them on they will take on an entirely new look. They will take account of his unorthodox shape and his calipers and hang beautifully, making him a fashionable lad of his age.

And, what's just as important to him, they will cost him little more than the price of the material.

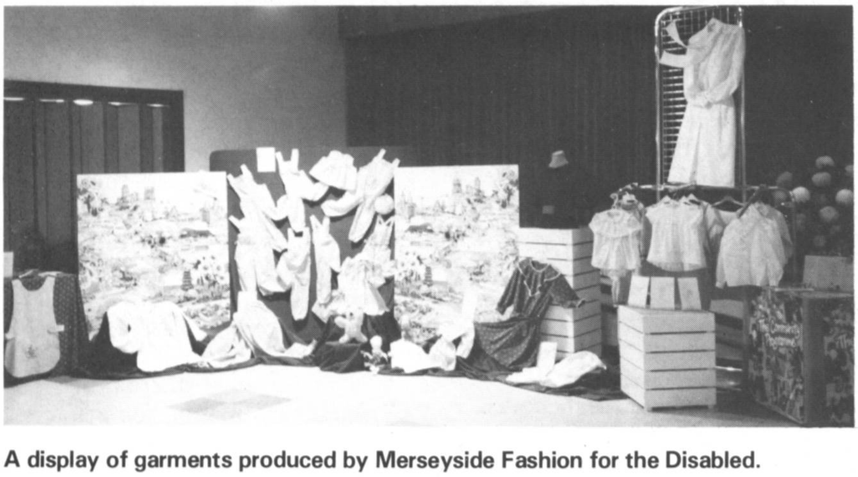
This is just one of an increasing number of garments coming out of the doors of this new Merseyside fashion service, partly staffed by disabled people for other disabled. It was started in September by Liverpool ASBAH, and encouragement and advice was given by Nellie Thornton of Fashion Services for the Disabled in Ilkley, West Yorkshire.

Marks and Spencer paid for all the necessary equipment to get it going, and the Manpower Services Commission is financing the running of it for at least the first year, under the Community Programme.

The scheme offers a service to the disabled community, and its other main aim is to provide employment and training for young people with physical disabilities over the age of 18.

Fourteen young people with spina bifida and hydrocephalus and other physical handicaps are learning dressmaking on a one year course under the supervision of skilled staff. After an initial basic training period, most of them should be able to join the 'task force' section working on made-to-measure clothes for disabled customers who have difficulty in buying ready-made garments.

The aim is to provide fashionable, practical clothes, specially adapted and ingeniously designed and cut to cope with awkward figures and the problems of having to wear surgical and other appliances. The trainees who are not involved with the 'task force' work in the 'craft room' where they concentrate on making all manner of smaller items — soft toys, play items, novelties and gifts.



A display of garments produced by Merseyside Fashion for the Disabled.

Cathy Willcock helping Marie Titherington in the basic skills of sewing.

Jackie Cooklin the workshop manager hopes that the craft room will soon be able to make accessories, such as scarves, belts etc. to go with the mix-and-match outfits ordered by customers.

This dual role of the workshop is something that has evolved over the past few months as it became apparent that not all the trainees would be sufficiently skilled to be able to work on customers' cloth, as part of the task force.

Some of the trainees are full-time, while the others put in 20 hours a week. They are paid by the Manpower Services Commission at the rate of £72.10 per week full-time and £52.50 part-time.

Their abilities vary enormously. One trainee, Joan Powell, who has hearing problems, is now working on whole outfits for customers, and Maria Titherington, who has spina bifida, is also proving to be a competent seamstress. Others are achieving progress at their own rate. Jackie hopes it may be possible for suitable trainees to take a City of Guilds exam at the end of the year's workshop course.

Since the workshop opened on September 3, Jackie and her staff have come gradually to understand the trainee's particular problems, and their limitations, as well as their skills.

"I have never worked with disabled people, so it has been a

e wo[illegible]oom as she and other trainees learn the

process of learning for me'' she said.

The main qualifications for a trainee at the workshop is their own motivation — they must want to be there. They must have a reasonable amount of dexterity, be able to arrange for their own transport to and from Tudor House and be sufficiently independent to cope with their own personal needs. Financial help with transport is available through MSC's 'Fares to Work' scheme. Before being accepted at the workshop they have a limited aptitude test and a formal type of interview.

Apart from Jackie there is one senior supervisor and one designer, two other supervisors, and a full-time care assistant who is also involved with teaching sewing.

Jackie's background is in the fashion trade. She used to run her own company making top fashion garments — jeans in particular — and was involved with the Youth Training Programme. She is employed by the Manpower Services Commission on a one year's contract.

Her comments on the job: "I've never been so totally absorbed with my work as I am here".

She started at the workshop in June, "when the only equipment I had was a pencil and rubber — not even a telephone", and spent the next two months working out the design of the rooms, taking into account, always, the need for safety.

She started to build up a good relationship with the local business community who have already shown their readiness to make special efforts for the workshop. She was able to enlist the help of local firms to design and manufacture special equipment, including adjustable height sewing tables, and a device to enable trainees with no use of their legs to safely and comfortably operate an ordinary sewing machine.

News of the service offered by the workshop travelled fast and plenty of orders are coming in. Customers choose and pay for their own fabric, which Jackie usually manages to get at a very reasonable rate, and apart from contributing something towards the trimmings, pattern and toile, they have nothing more to pay. The work is carried out free.

The workshop, of necessity, provides a very personal service and sometimes several fittings are required to get a garment right. Many disabled customers are shy about being measured and it takes time to win their confidence and to be able to discuss with them the right kind of outfit. This is the kind of service at which Jackie excels.

She is the kind of person who makes people feel immediately at home and at their ease. Richard Reddington is the wizard with the scissors who takes great pains over design and pattern cuttings. He's been up to Fashion Services for the Disabled to get advice and ideas.

It has proved an advantage that in another part of Tudor House there is a daily nursery for spina bifida children. It too is run by Liverpool ASBAH.

A specially adapted sewing machine that can be controlled by pressure from the machinist's chest. This leaves the arms free to guide the fabric.

The children proved useful models for the workshop when it came to trying out the designs that would accommodate awkward shapes, calipers and other appliances.

The workshop has put much more life into Tudor House. About ten years ago it was extended under an urban aid grant, to provide the nursery extension, and another wing which was intended to be a workshop. But lack of resources meant that this wasn't a possibility — that is until last year when Marks and Spencer in Liverpool stepped in and offered, as part of their centenary celebrations, to back Liverpool ASBAH and pay for the setting up of Merseyside Fashion for the Disabled.

Marks not only put the workshop on its feet, they also refurbished a lounge in another part of the Tudor House, and are financing a filter system for a hydrotherapy pool.

The representative from Marks & Spencer gets a taste of Ken Dodd's tickling stick at the grand opening of the fashion service.

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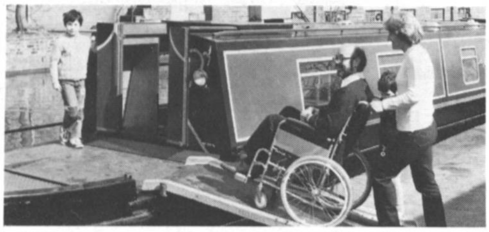

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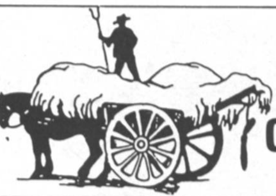

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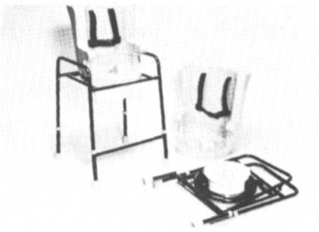

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Hydrocephalus in older children

Problems can return — and sometimes they are not easy to spot

Dr Pat Tomlinson, M.B., B.S., D.C.H.,
School Medical Officer.
Lord Mayor Treloar College, Alton, Hampshire.

THERE ARE many questions to be asked about the shunt control of hydrocephalus. Is hydrocephalus a problem of infancy only? Is there such a thing as arrested hydrocephalus? Is a person with a valve ever totally free from problems?

The great majority of babies born with spina bifida go on to develop hydrocephalus, and now between 90% and 95% have a valve (or shunt) inserted in the first few weeks of life to control this. Some babies have to have several operations on the valve in the first year or so, and others just have the lower catheter lengthened once or twice as they grow. A larger number of children had their valves inserted in the early weeks and did not need any further operation. The hydrocephalus was considered arrested and the valve, although still in place, was thought not to be needed.

Unfortunately it has gradually become apparent that a small proportion of these children do have further problems, and they may show signs of increasing hydrocephalus at any age. Most of the children develop headaches and other physical symptoms which make it obvious that the valve needs urgent attention.

The cerebro-spinal fluid around the brain is constantly being produced and normally drains away into the blood stream. In hydrocephalus there is excess fluid because the drainage system fails. Instead a valve is inserted to drain the fluid from the head to the blood stream. When the valve is blocked the fluid can no longer drain away and so it accumulates under increased pressure. The raised intra cranial pressure causes symptons due to the consequent increased pressure on the brain tissue.

If this happens suddenly it frequently causes headaches, often with pain on movement of the head. It may cause a wide variety of other symptoms, including vomiting, drowsiness, fits and loss of consciousness. These are usually very obvious and everyone is aware that the valve is not working.

Unfortunately in some children the symptoms are not obvious and characteristic and it may take a long time for parents, teachers and doctors to realise there is a problem with the valve. Sometimes when a child has a high temperature with a urinary infection, or flu, this appears to upset the control of the fluid by the valve and there may be symptoms of raised intra cranial pressure. This may settle as the infection clears, or it may highlight the need for a revision of the valve.

If the valve is only partially working, or if it has not been working at all, but the need for a working shunt recurs, there may be a very slow rise in the intra cranial pressure. The symptoms from this may be quite different from a sudden rise in pressure, and may progress insidiously over a long time. There is a small and persistent number of children who, slowly, over a period of many months, may develop increasing hydrocephalus for no apparent reason. They may have none of the usual signs or symptoms which might lead a parent or doctor to think that there is anything amiss with the valve.

If there is a slightly raised intra cranial pressure, it is not unreasonable to assume that the function of some of the brain tissue may be insidiously affected. One of the most obvious ways in which this may present is in any new eye changes, such as a new squint or a new or increasing nystagmus, an involuntary flicking movement of the eyes.

Another way in which a child may be affected is in a deterioration in performance at school. Sometimes this may be so slight that the child does not actually do less well, but fails to make the expected improvement with age. If a parent or teacher suspects that a child is not doing well at school, a full assessment by an educational psychologist may show that there has been a marked deterioration in some parts of the tests.

Some educational psychologists acquire considerable experience in this field, and can pick up these changes very clearly, sometimes before the parents are aware of any deterioration in their child. We have had a few children at Lord Mayor Treloar College who have been well and symptom-free, but who have been found by their teachers to have some patchy academic deterioration, often in subjects like science. These children are then fully tested by our educational psychologist, and the results are often very helpful in assessing whether there is any actual deterioration in the test scores indicating new brain damage. If this is so, the children have been referred back to their hospital consultants, and in a few cases have been found on investigation to have malfunctioning valves and increasing hydrocephalus, confirming the suspicions of the teachers and educational psychologist. The deterioration has been halted after revision or replacement of the valve.

There are many parts to intelligence and these can all be tested by the educational

continued over page

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psychologist. There is the verbal side, which includes the ability to talk and use words, tell stories and write essays. Then there are tests of the ability to appreciate and manipulate patterns and shapes, which indicates whether a child has spatial and perceptual problems. There are also tests assessing short term memory both visually and auditorially presented.

The spina bifida child is usually very good on the verbal side, but has great difficulty with the performance of more practical tests, like sorting shapes and doing jigsaw puzzles. This may be due to damage to the brain tissue in the first few weeks of life as the hydrocephalus was developing. if there is a recurrence of hydrocephalus in later years it appears to be the same areas of intelligence which become affected first. So the child may continue to be good at English but finds maths and science difficult. There may also be a deterioration in short term memory, and they may become increasingly unable to organise themselves and keep to timetables, etc.

It seems therefore that we can no longer assume that hydrocephalus may be permanently arrested. If a child or young adult changes in behaviour or develops some strange symptoms, it would be worthwhile investigating to see if there is any increase in their hydrocephalus.

Study Day helps over 70 people share experiences

THERE was a very enthusiastic response to ASBAH's Study Day on Hydrocephalus held at National Office at the end of November.

ASBAH's Conference Room was packed with over 70 people — mainly parents, as well as teachers from special schools, and field workers. Dr V Hill from Australia who was in England studying various aspects of spina bifida and hydrocephalus also attended.

The room could have been filled again, as there was a waiting list of over 60 people.

The first speaker was Dr Roger Bayston of the Institute of Child Health (see below).

Ms Gillian Stellman, Clinical Psychologist, and Ms Maggie Gilmore, Senior Ward Sister from Booth Hall Children's Hospital, Manchester talked about the special unit for new born and premature babies with hydrocephalus. They referred to the noticeable increase in the number of hydrocephalic babies being referred to them — from about 40 over a seven year period, to 20 in just one year.

Mr Andrew Williams gave a humerous and revealing insight into the way in which he and his wife had tackled the challenge of bringing up their son Glynn, who has hydrocephalus, and the unorthodox approaches they had had to adopt.

The different procedures carried out by hospitals investigating possible shunt problems varied in different parts of the country, and different parts of the world, explained Mr Roger Brereton, Paediatric Surgeon. He spoke of some of the procedures that parents were likely to meet.

He reassured parents worrying about how physically active they should allow their child to be. "Let them be boisterous like any other children. By and large relatively minor accidents would not cause damage to children or to the valve" he said.

"Children with Hydrocephalus at School" was the subject of Dr Patricia Tomlinson, Medical Officer of Lord Mayor Treloar College in Hampshire where she has kept the records of 142 pupils with spina bifida and hydrocephalus at the school over a four year period. (Dr Tomlinson has written a special article for LINK on page 15).

ASBAH's Research Officer, Mrs Leonie Holgate talked about the different perceptual and learning problems of young people with hydrocephalus.

(LINK will carry a report on her talk in the next issue. We feel that her observations and suggestions for ways in which parents can help, will be of great interest to many readers.)

Why regular checks are important early on

SPEAKING at ASBAH's Study Day, Dr Roger Bayston emphasised the need for people with valves to have regular check-ups. Dr Bayston of the Institute of Child Health said this was particularly important in the first six months after the valve was fitted.

Regular checks would detect problems at an early stage and could avoid the development of serious and sometimes fatal infections, such as shunt nephritis.

He called for the setting up of facilities for testing in major centres in the UK. He suggested one centre for Scotland, and others in Newcastle, Liverpool or Manchester, Sheffield, Birmingham, Bristol and London.

Dr Bayston said that the problem at present was that many people found it very difficult to find someone to carry out a test. However, he suggested that if this were the case they should go through the hospital consultant or general practitioner who would arrange for blood to be taken. This could then be sent to Dr Bayston and his team at the Institute, and they would carry out the necessary test.

Dr Bayston spoke about the many different causes of hydrocephalus not connected with spina bifida. He mentioned in particular intra-ventricular haemorrhage which could occur in very premature babies. Because of the increase in the number of premature babies being born, there has been a marked increase in the number of babies with hydrocephalus, he said.

The mother of an 8-year-old boy with hydrocephalus poses the question —

A self-help group concerned with hydrocephalus?

by
BARBARA HAY

HAVE YOU, as a parent of a hydrocephalus child, wondered where to turn for information and help: how you could make contact with and relate to people with an identical problem?

This was my difficulty when my son, now eight years old was diagnosed as having hydrocephalus at four months and it was this difficulty which, periodically over the years, left me with a sense of isolation.

Like me, the chances are that at the time of the first diagnosis you had never heard of hydrocephalus and the basic technicalities instilled a tremendous fear as to what the future held for the child. The lack of information and true understanding of the medical terminology no doubt contributed to this fear.

From your early hospital visits you may well have gained the impression that hydrocephalus was synonymous with spina bifida. As we all now know a child, or an adult, may have hydrocephalus only. However a very large proportion of those with spina bifida are also afflicted by hydrocephalus.

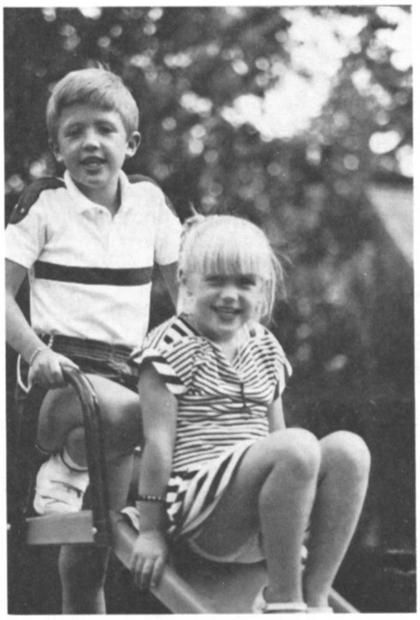
As with other parents with whom I have spoken, my eight years experience has been gained the hard way. Our problems are; unreliability of the shunt; high pressure/low pressure; infections; and the many other medical/technical difficulties.

How are we to know when the shunt is blocked? How are we to determine an immediate urgency? What signs and symptoms should we be looking for to convey to the consultant?

As related issues, how can we cope, with the stresses that these problems produce? For example there is repeated hospitalization and the effects and strains on the family; educational and behavioural problems; the need to help our child deal with his/her problem.

Unfortunately, help with these varied difficulties seems almost non-existent at local level. It is difficult to generalize but it would not be wholly untrue to state that few local G.Ps and hospitals have had regular contact with hydrocephalus patients.

It is this local contact which is so important both in terms of medical advice and support from other parents. Regrettably it is not readily available. The incidence of hydrocephalus is somewhat rare in a small geographical area. Or is it? Is this your experience?



Paul Hay and his sister, Claire.

There is, of course, an organisation which deals with these very problems, namely ASBAH. You are obviously aware of the organisation as evidenced by the fact that you are reading this, but, did you not make your first approach with some temerity? Did you not feel as I did, you were encroaching upon their valuable time and services thinking, that their prime concern would be for spina bifida?

In fact, this is not the case but the Association accepts that such a situation has developed and, as a result, they are not in regular touch with a large majority of those with hydrocephalus. I have discussed this with officers of the Association and they are most anxious to dispel the psychological circumstances which have created this unfortunate situation.

They would very much like to:

a) attract parents with hydrocephalus children, and also those who in later years have developed hydrocephalus; It should not be overlooked of course, that the children will reach adulthood.

b) improve their existing services for those with hydrocephalus.

How can these desirable aims be achieved? If my assessment of the psychological barrier is correct, then the answer is that we must break down this barrier. But how?

I respectfully submit that a Self-help Group specifically for hydrocephalus is the key — not as a separate organisation, but working under the umbrella of ASBAH. I dislike the word 'separate' but in this context I think that if an impression could be publicly conveyed that the Association contained a 'specialist group' then that psychological barrier would be quickly broken down.

This would highlight the Association's information activities and interest in hydrocephalus, and act as a 'clearing house' for parents to get in touch with each other with a view to forming a self-help network. The network could put forward ideas for research, medical information, etc.

None of this activity would be at the expense of the aims and objectives of those with spina bifida. Indeed, I visualise an advantageous 'spin off' for spina bifida. It has been established that a large proportion of people with spina bifida have hydrocephalus and they would feel, quite rightly that they could benefit considerably from this specialist group. Surely it would be reasonable to assume that over a period of time a greater degree of specialist expertise would be acquired — more importantly could be dispensed beneficially.

What do you think? Does the idea have any merit — or have you other ideas?

Please write and let me know: Mrs Barbara Hay, c/o ASBAH, 22 Upper Woburn Place, London WC1H 0EP.

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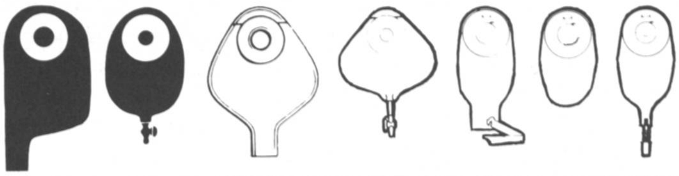

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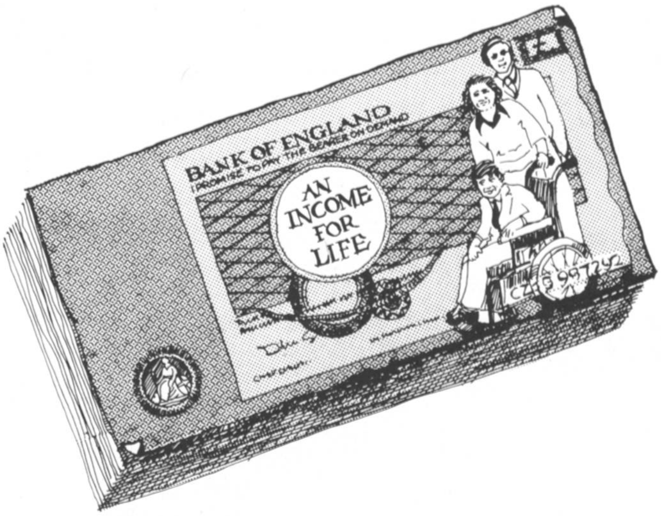
IN THIS last article of the series, by John Taylor, the subject matter is the protection of income in the event of illness or accident.

Some advice on guarding against misfortune



SHOULD a husband or wife become disabled either through a prolonged illness or a serious accident considerable expense can be incurred in two ways. A partner in an occupation would eventually lose their income; if an individual is at home caring for the family then a paid replacement may have to be found.

Of course, the State will help in a small way but it will not make up the total financial loss. I have met people who have lost their business, house and even their marriage because illness has prevented them working.

As with the problems highlighted in earlier articles there is a solution. By taking out some form of health/accident insurance policy it is possible to alleviate or even eliminate the financial burden imposed by that unexpected illness.

For the purposes of this article I am discounting hospital insurance as it normally only caters for that period spent in hospital and little else. This is not to say it is not a "good idea", it just does not help replace lost income.

There are basically two types of health/accident insurance policies. One is called Permanent Health and the other Accident and Sickness insurance.

As the name implies, Permanent Health Insurance guarantees cover up to a certain age regardless of the change in your health. Should you develop a recurring illness that causes 'claims' you will still be paid out each time it recurs up to the age you opted for at the beginning of the policy. The usual ages offered by companies are 55, 60, 65 or 70. The longer the period covered the more premium to be paid.

At the beginning of the policy you will also have a number of other options to choose from. The first will concern the deferment period required; this means deciding how soon after an illness or accident you would want paying. The usual deferment periods are four weeks, thirteen weeks, twenty-six weeks and fifty-two weeks. It is, therefore, important you know for how long your occupation would pay you if you were 'off sick'. The shorter the deferment period the higher the premium.

Each time you are unable to work due to illness or accident the insurance company will pay you the amount agreed after you have been off work for the deferment period. Should you be ill for the rest of your life then you will be paid up to that age selected initially, e.g. sixty-five. I would stress that you never receive money for the deferment period.

Another option available is whether to have an increasing or level income. Bearing in mind inflation, it is perhaps a good idea to consider an increasing benefit.

The maximum benefit allowed by the majority of companies is either 66% or 75% of your present income. This allows for state assistance and a lower day to day outlay, e.g. no fares to work. So, although it may appear that you will receive less if ill, in fact you should not be worse off.

At present this income is not taxed until it has been paid for a full fiscal year. This means that if you were to start to receive an income in June 1985 then you would not pay tax on it until you reached April 1987, a full fiscal year being April to April in broad terms. If payment started in March 1985 then it would be taxable from April 1986 should you still be receiving it.

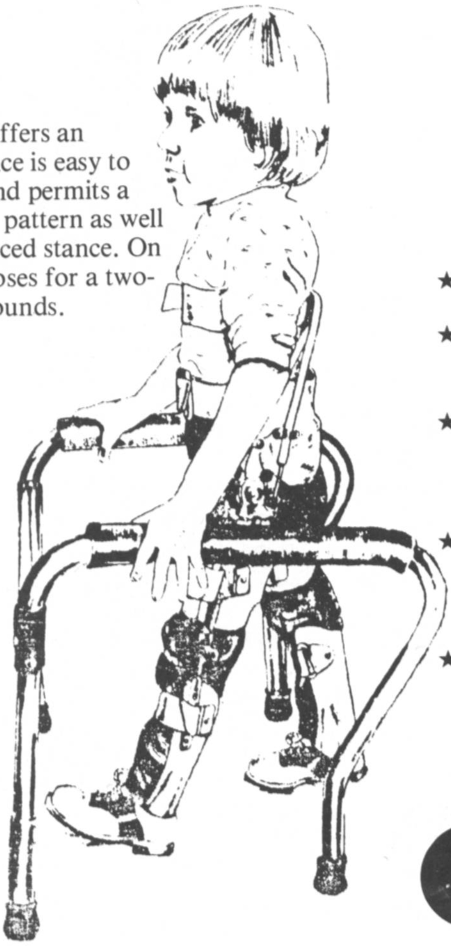
This tax situation also applies to accident/sickness policies. The details, however, do differ to those of Permanent Health. It is usually an annual contract much like a car insurance policy. As with a car policy, on renewal, you could be declined or have restrictions put on the policy, e.g. excluding a certain illness because you have had a claim and it may recur.

The main attraction of an accident/illness policy is the deferment period which is usually seven days. This is ideal for someone who is paid weekly and would have a financial problem if pay were to cease after a week's absence from work. It is also of interest to self-employed people who, by the nature of their business, may receive no income immediately they stop working.

The selected benefit is normally paid for a maximum of 104 weeks, thereafter you are 'on your own'.

Should you consider an accident and sickness policy be certain you know when the company *actually* has to pay you. I learned, to my horror, that certain low premium companies only pay out at the *end* of the illness. This could mean waiting two years for your money. Thankfully very few companies operate this system, but, in your own interest, do ask for confirmation of the situation.

I have not given any premiums for the policies mentioned as they vary with occupation, deferment period, age, plus the options available. Should you require more information or an idea of cost of such plans please contact me via ASBAH.



The Reciprocating Gait Orthosis

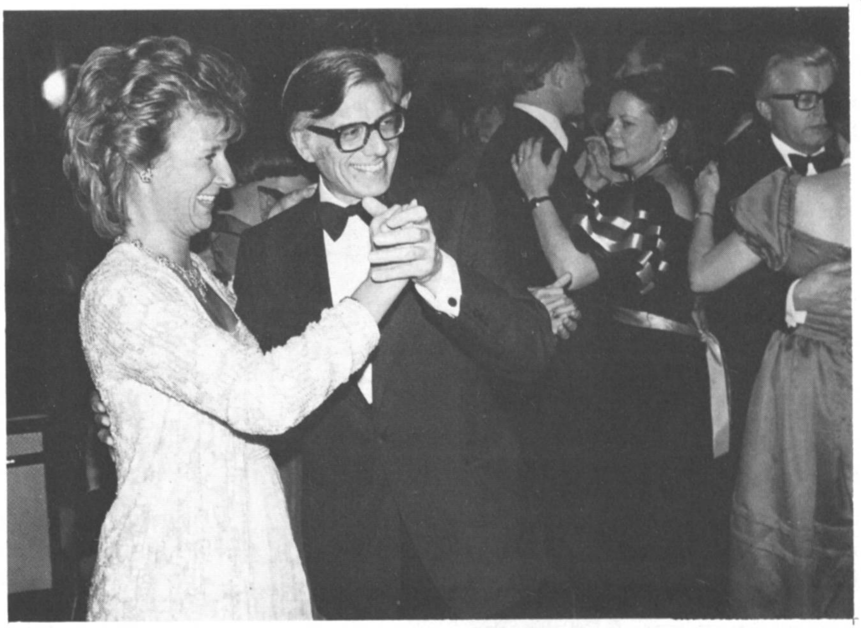
IT has been accepted that part time ambulation in some fashion is highly desirable at least for physiologic benefits for any wheelchair patient. Also in many instances for this group of patients with severe biomechanical deficits, prevention and/or correction of deformities is an important function provided by the orthosis. Otherwise the active unopposed, or weakly opposed muscle may cause progressive deformity.

The Orthotist now has the tool that has the versatility, adaptability and convenience to accomplish these requirements.

Traditionally bilateral Knee Ankle Foot Orthoses with pelvic bands and hip-joint locks provided the spina bifida with sufficient control to execute a tripod gait. This form of locomotion at best is unnatural and highly wasteful in energy.

Experience indicates that this innovative orthotic system which co-ordinates leg motion, enables the spina bifida patient to walk in a reciprocal mode that is more natural and requires a lower output of energy. The average weight of the completed orthosis is in the range of 6 – 7 lbs.

The key to the system is a cable coupling to each extremity that in standing provides hip joint stability, yet instantly permits unilateral hip joint flexion, when a step is attempted. Only when sitting is intended need the patient disengage the cable by unlocking a latch, this in effect lengthens the cable to permit full bilateral hip flexion.



ASBAH Patron, H.R.H. The Duchess of Gloucester and Chairman, Mr. Davis Bryant at the Opera Ball.

First Computer Auction boosts Opera Ball

PREDICTABLY enough the closing weeks of 1984 were a very busy time for members of ASBAH's Appeals Department.

Our late autumn event, The Opera Ball, proved to be a most memorable occasion in the glittering surroundings of one of London's most glamorous hotels — Claridge's. Because of the limited capacity of the banqueting suite, the occasion had the air of a private party and all our guests entered into the spirit of the occasion magnificently.

The Computer Auction, held for the first time on this side of the Atlantic, produced a remarkable £3,000 from the 150 bidders present and as a result of this success the computer software company who wrote the programme are interested in marketing the idea to other fund-raising organisers. ASBAH will receive a 10% royalty.

The whole evening was a classic example of how quality can surpass quantity when it comes to generosity and our social Chairman, Mrs. David Stevens, has received many compliments and requests for details of forthcoming events.

On a much larger scale, 10 December was the date of the Biggest Office Party in London and the day started well with a piece on BBC's Breakfast Time Television in which organiser Jane Hayman presented a most persuasive case as to why people should hold their office Christmas party whilst benefiting us at the Hammersmith Palais.

As a result the evening was well attended and resulted in many memorable moments as party-goers vied with each other to hire kisses and cuddles from the French Maid, the Roly-Poly Lady and the Japanese Tarzan, as a very special Christmas treat for bosses and secretaries alike.

These touching encounters were recorded for posterity by ASBAH's on the spot Polaroid camera crews and it is a pity that we could not retain the negatives as this might well have proved a valuable means of fundraising in the future!

Pausing only to nibble on a turkey leg and have a quick spoonful of Christmas pudding, our intrepid team rushed back to work after the break in order to throw themselves into a most daunting schedule of innovative ideas for the new season.

Amongst the plans are several events for the macho minded, including a Royal Marine Commando assault course, Escape and Evasion from a rocky island off the Pembroke coast, a contest to find the Young Yachtsperson of the Year and, as ever, our hardy perennial for the hardy few, Mountain Express, this year in the capable hands of HQ Wales.

Theatre nights, fashion shows, golf tournaments, conversationalist contests and many other old and new ploys are waiting to beguile past and future supporters and as ever we would welcome the presence of any readers of LINK.

Just let us know what your particular preference is and ambitions are and I am sure that we will be able to provide you with an occasion to remember during 1985.

JUDY KAY
Appeals Director

Special centre offers the chance to try something new

THE KIELDER ADVENTURE CENTRE set on the shores of Kielder Water in Northumbria is purpose-built for disabled people and their families and equipped with everything from an indoor heated pool to a shop, library and adventure playground.

It offers the chance to canoe, sail, fish, birdwatch, cross country ski (when the fells are blanketed in snow), and a host of other activities. The Centre can cater for those disabled visitors who wish to be independent, or come with a family or in a group, as well as those who rely on the services of the experienced resident staff.

There is breathtaking scenery just waiting to be enjoyed and lots of history to discover.

If you'd like more details contact: Jim Wainwright, Kielder Adventure Centre, Low Cranecleugh, Kielder Water, Falstone, Hexham, Northumberland NE48 1BS. Tel: 0660 50232.

LINK INDEX — Issues 90 – 95

BELOW is a list of the main articles which appeared in LINK during 1984 — issues 90 – 95. If you would like back copies or a copy of a particular article please get in touch with Beverley Holland, the Information Officer at National Office. She also keeps a list of useful LINK articles from previous years.

SPINA BIFIDA AND HYDROCEPHALUS	Issue
Research sponsored by ASBAH	91
MEDICAL AND GENERAL HEALTH CARE	
Baby's Mobility, Mary Barton	90
ASBAH survey highlights poor hospital services for over 16's	91
Sussex Clinic for Young Adults	92
Pressure Sores and Ulcers, S. J. Watson, J. E. Hewson	93
Epilepsy, J. Keen	94
Bowel Management, A. M. K. Rickwood	95
DISABLED LIVING	
ORLAU's Swivel Walker, Para Walker	91
LINK Special No. 1. Children's Footwear, and Intermittent Catheterisation	91
Access Committee, A Goldthorpe	91
Fashion Services for the Disabled	92
LINK Special No. 2. Mobility Aids	93
Financial Advice, J. Taylor	93, 94, 95
Seating for disabled drivers, L. Holgate	95
ALLOWANCES, GRANTS, ETC.	
Family Fund	90
The Severe Disablement Allowances, L. Lennard	93
EDUCATION	
After 16 Campaign launched	90
The 1981 Act — What it did not say, Faith Seward	91
The Fortune Centre	95
ACCOMMODATION	
Southampton flats scheme	93
LEISURE	
Five Oaks Courses	90
Liverpool Garden Festival	90
Kielder Adventure Centre	91
Camping for the Disabled	91
Skiing for the Disabled	94
MISCELLANEOUS	
Photo feature, Howard Griffin	90
Ten points for keeping a marriage together	92
British Rail plans	91
LIFT Weekend	92
IYDP Holiday Fund	92
Irish Association Summer Project	92
ASBAH's 18th Birthday Party	93
Mobility and Independence (B. Rail), Mrs. L. Chalker, MP	94
Special seven page Report on work of Local Associations	94
LIFT Roadshows	94
Who needs whom the most? Mrs June Davies	94
International Year of Youth	95
ASBAH's Annual Meeting	95

CLASSIFIED 'ADS'

The advertisement rate is:
£2.50 for up to 30 words. £3.75 for 30-45 words.
£5.00 for 45-60 words.

Please send remittance with your advert.

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

Adverts for the next LINK (March/April) should be in by February 10. Send to the Editor Mrs Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

SELSEY, Sussex. Purpose built 7 berth mobile home, fully equipped for wheelchair users. Cot available. Licensed site. Details: Mrs/Mr Holmes, 11 Grove Road, Ashtead, Surrey. Tel: Ashtead 76730.

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

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

EXCHANGE & MART

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

Ortho Kinetic Chair for sale. £100 or offers. Please apply to: The Secretary, KASBAH, 4 Scott Close, Ditton, Maidstone, Kent.

B.L. Mini Clubman Estate for exchange or part exchange. High top and electrical ramp/back door. Suitable for wheelchair user either to drive or be transported. Hand controls to be removed on sale. 26,000 miles. Good runner. Wish to exchange or part exchange for Metro or other small car (*must be automatic*). £2,000 in part exchange but would prefer a straight swop for a T reg or after.
Contact: Freddy Williams. 01-305 0294 (4-6 pm), or 01-311 8519 (9.30 am-3 pm) and leave message. Greenwich, S.E. London area.

Mini Clubman Automatic, High Top, Gowring Conversion, for sale. R. Registration. Electrically operated ramp. Handcontrols available. Well cared for and well maintained. Just under 20,000 miles on the clock. Quicklock clamps for wheelchair. £2,250. Tel: Esher 64356.

ASBAH Publications

Children with Spina Bifida at School Ed. P. Henderson, CB, MD, DPH	70p
The Handwriting of Spina Bifida Children Joan Cambridge and Elizabeth M. Anderson	£1.60p
Sex for young people with spina bifida or cerebral palsy	£1.75p
The Nursery Years Simon Haskell and Margaret Paull	60p
Little Joe (A Grandmother's story) Winifred Foster	40p
Life and Death — thoughts on bereavement	75p
Making our Way — individual experiences of young people with spina bifida and hydrocephalus	£1.20p

All the above prices are inclusive of postage and packing.

Information leaflets	100 for £4
Fact sheets — (on a wide variety of subjects)	up to 10 copies free

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free (up to 10 copies) from national office. Translations are into Bengali, Gujarati, Hindu, Punjabi and Urdu.
Welsh language sheets are also available — up to 10 copies free

Please send at least 30p postage.

Scottish Spina Bifida Association BOOKLETS

The Spina Bifida Baby by O. R. Nettles, McSP, ONC.	40p
Growing up with Spina Bifida by O. R. Nettles, McSP, ONC.	35p
Keeping Fit by Jean M. Temple MCSP	10p
Self Help with Spina Bifida by E. Wilson and E. Taylor	10p

Postage and packing is extra.
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW.

JOHN GROOMS HOLIDAYS

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

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

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

Holiday Chalet: Near Skegness (Lincs)

London Holiday Flat: London, N.4.

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

Bungalow: In the heart of the Norfolk Broads

Canal Holiday: In adapted narrow boat.

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

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