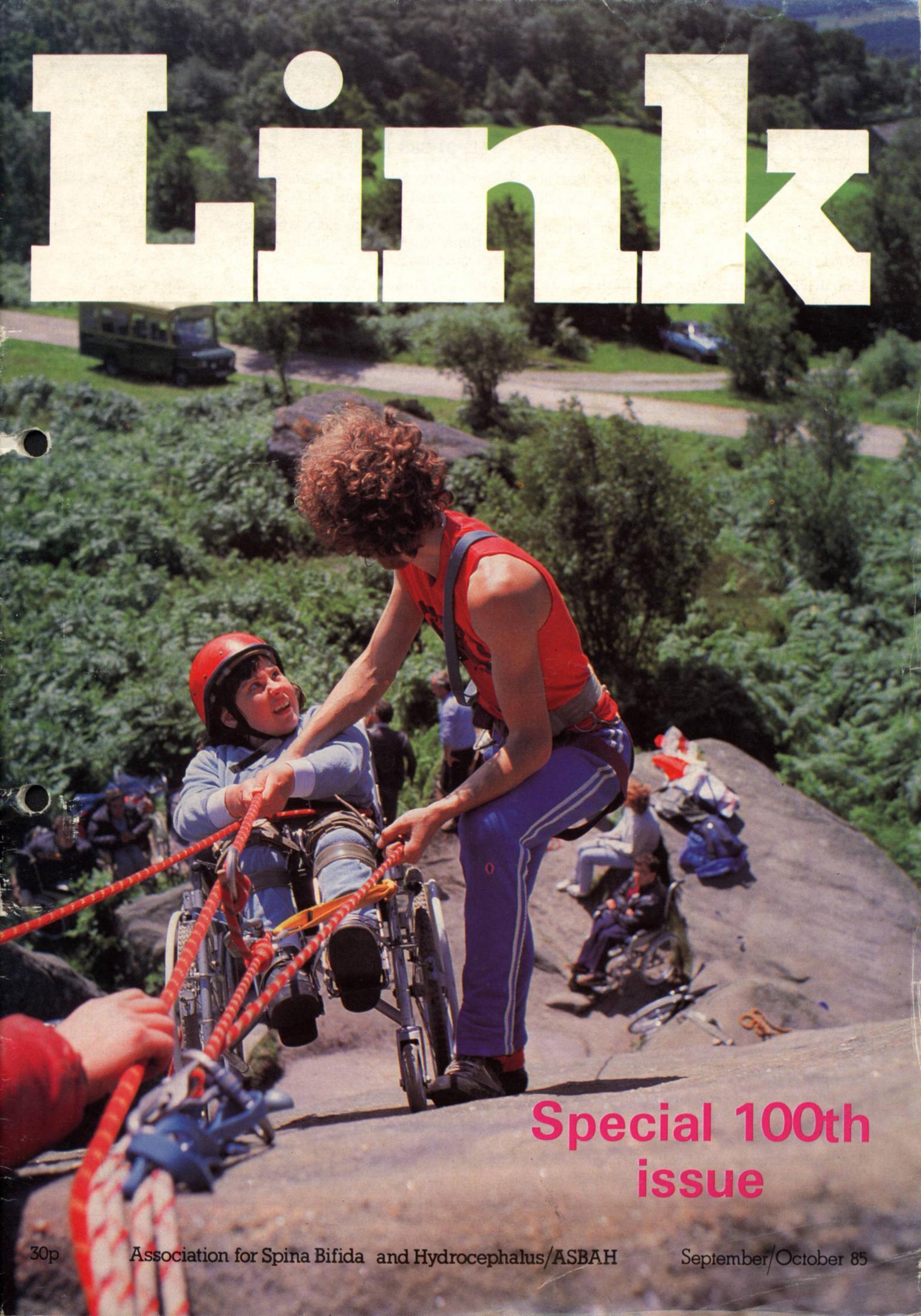


Link



Special 100th
issue

Association for Spina Bifida and Hydrocephalus (ASBAH)

22 Upper Woburn Place, London WC1H 0EP

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

Editor's Note

THIS centenary issue of LINK comes to you with a special full colour cover in celebration. But it's back to the more economical black/white and green cover next time!

It has been some time — since the 54th issue — that LINK changed its style, so we thought it an appropriate issue to introduce a new, brighter and airier style which we hope you like. We hope, too that you find the content interesting and informative.

An important part of the new look is participation by local associations and individual readers. We need to hear from *you* regularly. So if you want your local association mentioned, or your view put across please do send it in. News, views, photographs, snippets of information all are welcome — as well as lively and stimulating letters for the letters page. What are your views on the letter in this issue on the question of whether young people who are disabled should be expected to collect in the streets for organisations like ASBAH?

The first spina bifida granny

The hunt for the first spina bifida grandmother continues and there is a new 'champ' — Mrs Margaret Spencer, 73, of West Cowes in the Isle-of-Wight. She has two grandsons and the eldest is 25, which means she easily outstrips Marjorie Illman of Horley, Sussex, whose oldest grandchild is only 15. Mrs Spencer hopes to be a great grandmother in November.

Sue Gearing, Editor

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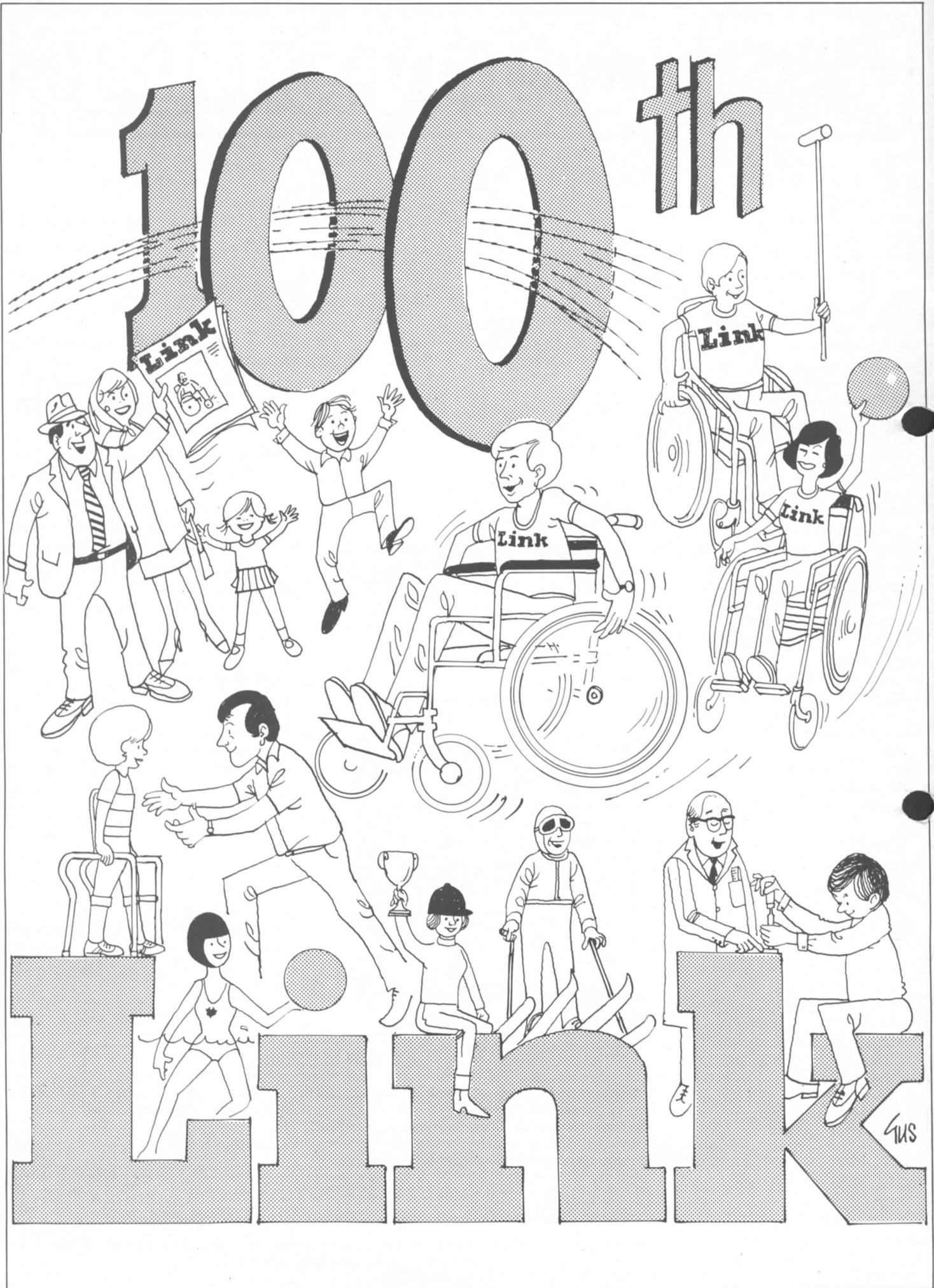
COVER PICTURE

Reaching the heights, at Brimham Rocks, North Yorkshire. Samantha Bell is one of the young people on an ASBAH Special Activities holiday at Five Oaks this Summer. There she tries her hand at abseiling in a wheelchair!

Photo: by Howard Griffin — the very professional amateur photographer whose work has appeared in LINK several times before.

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 October 5. Send to the Editor at National Office.



The last ninety-nine



by the Editor,
SUE GEARING

THIS is the 100th issue of LINK and the 75th that I have edited.

LINK was first issued in the Spring of 1966 as a bi-annual magazine, but very quickly it came out quarterly, and demand for more frequent publications resulted in the appearance of a regular bi-monthly magazine in 1973. Over the years there has been an increase in the volume as well as the quality of information and comment available to the readership. The broad mix of information and comment in LINK has continued throughout its life, and it would appear to have been a successful format, which has stood the test of readers' requirements for the past 19 years. I have always considered LINK principally as the members' magazine, able to provide the information which they require and thereby allowing each reader the opportunity of considering him or herself as one of the ASBAH family. LINK has provided guidance and contact for those members who have been unable, at times, to join with others in their area for the benefit of mutual advice and support. But the magazine has also a considerable number of readers from the interested professions and they, too, have always considered it as a source of reliable information. I believe that LINK, through its editors and contributors, has achieved the aspirations of those early days in 1966 when it was considered vital that a journal of information and contact was most essential for the unity of the organisation. It may still be impossible to improve on the words used in the Chairman's Report at the first AGM in 1966: "Nothing we have done has contributed more to the benefit of the members throughout the country than LINK". Its future success will, as in the past, depend upon its appeal to the readership. Does it meet with your requirements? Are there aspects of concern which are never, or rarely, mentioned? Are there groups of ASBAH's membership who feel that LINK is not relevant to them?

We welcome your constructive comments, as the future of LINK, as indeed of ASBAH itself, depends upon you.

R. H. TALLAMY,
Vice-Chairman, ASBAH Executive Committee

Over the years, through the contact I have made with individual families and ASBAH staff, I have had a unique inside view of the long-term struggle facing parents of spina bifida and hydrocephalic youngsters and the young people themselves. To look back through the pages of the last 99 LINKS is to see clearly the changing face of ASBAH.

The early issues reflect the embryo stages of the Association as one or two established local groups endeavoured to get things going on a national scale. LINK No. 7 was a Special to mark the launch of the first Spina Bifida Campaign (launched by Harry Secombe in March 1968) to raise money for publicity, more treatment centres, information services, field work, and research.

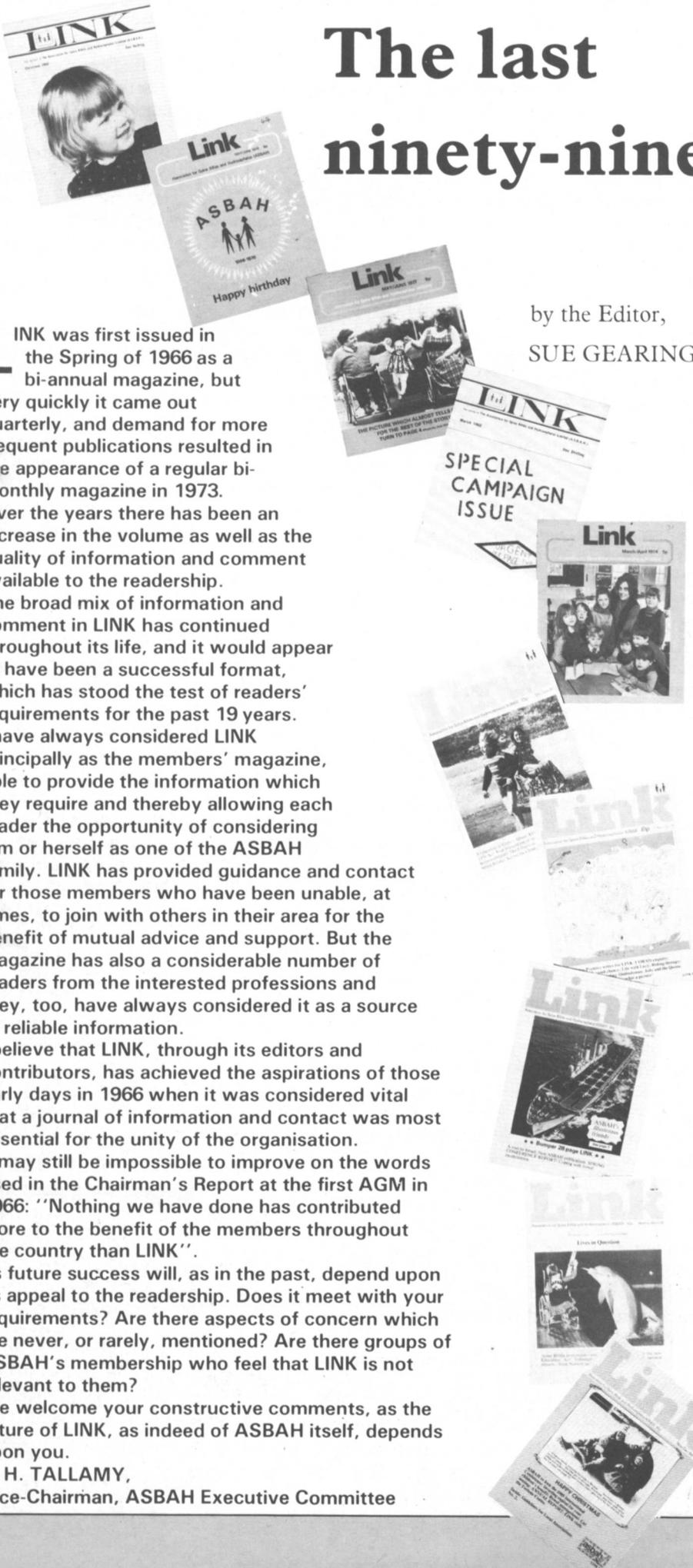
Early attempts through the pages of the magazine to find a new name for ASBAH bore no fruit.

"The name is difficult to project. It takes too long to explain; once explained it takes even longer to understand. It is a tongue-twister when spoken in full . . ." reported an early issue. But as the name of ASBAH has become much more familiar we seem to have become content with it. Certainly no suitable alternative has ever been suggested.

In the early issues there was greater emphasis on the care of the young child. As LINK has progressed that emphasis has shifted to accommodate the needs of the young people as they grow up. There have been articles on independence, training, diet, personal care, education, housing, benefits, sport and recreation, and the subject of sex started to infiltrate the pages in about 1977 — issue no. 49!

As young people with spina bifida and hydrocephalus have matured they have started to make their voices heard, albeit still on a small scale. We now see more articles in LINK initiated by the young people themselves — like the personal experience of intermittent catheterisation by a teenage girl in this issue.

Continued





For the first few years LINK was quarterly but soon it became necessary to publish bi-monthly as the Association gained momentum.

In 1976, the May/June LINK, No. 44 was a Special Souvenir Issue to celebrate ASBAH's 10th birthday. It carried a personal message from The Royal Patron, the Duchess of Gloucester, whose presence at so many ASBAH functions and her visit to national office in December 1974 have been recorded in print and pictures over the years.

Also in 1976 LINK recorded the opening of Five Oaks, envisaged then, pure and simply, as a short term care home, before the advent of independence training and special courses and holidays.

The conferences held by ASBAH have always been reported fully in the magazine and the accounts provide a unique record of these very important gatherings. The next issue will bring readers the content and flavour of the first International Federation Conference to be held in Britain, hosted by ASBAH, in Manchester later this month (Sept.).

Articles giving advice on the medical aspects and management of spina bifida and hydrocephalus have always been important, and many features in the earlier issues were contributed by Prof. John Lorber who has given much valuable guidance over the years. The first Chairman of ASBAH, Prof. R. B. Zachary, also provided helpful, informative advice in LINK.

As the magazine has increasingly attracted a much wider professional readership, we have been fortunate in being able 'to persuade' experts in many different medical and paramedical fields to contribute articles especially for LINK readers.

More and more, other magazines are seeking permission to reproduce LINK articles, and we are usually only too happy for them to do so.

The arrival of antenatal diagnosis and the possibility of early termination of pregnancy caused a good deal of debate, and ethical problems were discussed and covered in LINK. A special Supplement brought out in March 1982 and entitled 'Lives in Question' (copies of which are still available from National Office) looked at the issues concerned in the controversy over 'selection for treatment' of new born babies with spina bifida and/or hydrocephalus and care of new born babies.

Personal stories have been a mainstay of LINK. After all there's nothing quite like hearing how other people have coped, or failed to cope! As a sign of the times we have recently had articles about how young mothers with spina bifida have managed in bringing up their own children. In early issues many of the personal accounts were from parents describing their feelings on first hearing that their baby had spina bifida and/or hydrocephalus, and the attitudes of hospital staff towards them.

This issue is, of course, still very much to the fore as ASBAH endeavours to forge a good working relationship with hospital and medical staff so that the birth of a disabled child will, hopefully, no longer be exacerbated by lack of communication and understanding between staff and parents.

The spread of sporting and recreational facilities for the disabled in this country has been reflected in LINK, giving coverage to activities ranging from bird watching to skiing.

The early 'aids and equipment' page — written for a good many years by Owen Nettles, the former Appliances Officer — has broadened out to become a Disabled Living Page with contributions from our current Disabled Living Advisers, giving information not only on aids but about general personal care and subjects such as mobility.

Another important regular page in the magazine is devoted to money raising and as the Appeals Department has become established, more and more ambitious national fund raising functions have been reported.

The establishment of strong ties with spina bifida associations overseas has been evidenced in the pages of LINK with letters and articles from families in different countries. During IYDP, LINK carried an article from a different spina bifida association abroad in each issue.

From the early days LINK was read overseas, and today 800 copies of each issue are sent to all parts of the world.

It was issue no. 54 that really put LINK on a much more professional footing when it changed its style and increased in size to A4. There were 16

pages then. It has increased in stages since then and today has settled down to a regular 32 pages. With the help of the telesales department of ASBAH, the magazine is subsidised through the generosity of advertisers.

LINK has a circulation of 9,000 and as the magazine has become more 'professional' so, too, has the readership. The need to strike a balance between families' needs and those of doctors, physiotherapists, and teachers, etc., who read LINK is a difficult task.

Now the direction you want LINK to take in the next 100 issues is largely in the hands of you the readers.

In LINK no. 4 — the first anniversary of the magazine, the Editor at the time, Steven Hinchliffe, wrote: "Our object is two-fold. We want to be a link within the national Association — to bind parent to doctor, doctor to doctor and parent to parent. We also want to be a link with the outside world — to do what we can to help make the words spina bifida and hydrocephalus the household names that spastic and thalidomide have become . . ."

The second aim is on the way to being realised through ASBAH — and LINK — but there is still much to be done in the area of communication between families, and between families and professionals whether they be medical people or those working in local social service or education departments.

Communication won't be achieved unless there is a much greater participation by all the readers of LINK. I look forward to hearing from many of you, and to meeting some of you as I put together future LINKs.





The 1st

The first issue of Link came about after months of discussion with people in different parts of the country.

With the help of my former wife and a lady who had done the final typing, duplicating and putting together, I had published a newsletter for the Sheffield Association. At one of the ASBAH—Executive meetings I was asked to explore the possibility of producing a national journal. I made contact with others who were also doing local newsletters, people like Norman Kjeldgaard, in Scotland.

By letter, phone and a meeting in Manchester, we decided that we wanted a good quality printed magazine of about 16 pages. The name Link was chosen because of the need for something for all of the interested parties, the children, the parents and the professionals, involved in the blossoming Association.

None of the first contacts were experienced writers, and I realised that to have a good quality magazine we needed a good readable style. I had read a short article in one of the national newspapers by Mavis Davidson, about her distress at the lack of help during the illness of her child with hydrocephalus. I wrote to her and found her to be Mavis Cotsford, writing under her maiden name.

Mavis was a journalist and her husband Goff was a sub-editor with another national newspaper. They joined the team and with me seeking material, their expertise in editing and layouts, we were in business. (A few years later Mavis died, a tragedy for us all.)

The first few issues of Link were printed by a printer on my route home from work in Huddersfield. I well remember the first excitement of collecting 1000 in parcels of about 200. To save money I did the posting to different parts of the country myself. Copies of Link seemed to cover the living-room floor. I particularly remember the smell.

With Link making a profit from the start and circulation increasing rapidly with each early issue, following numbers were sent direct from the printers. One order I remember particularly was for 30 to Houston, Texas.

Meeting production deadlines was a problem. We gained some flexibility by quoting a season — Spring or Summer — for production dates. It was all very exciting, very hard work, and eventually a burden. Mavis took on the whole task, and it was her and Goff who helped most to give the quality to those early issues.

Stephen Hinchliffe,

The first Link Editor

Peter Whitehead of Rainham in Essex was only three when he was pictured on the cover of the first LINK.

Peter again featured in the magazine in 1975 — the 10th anniversary of ASBAH —; now aged 23 he is in the magazine again to celebrate its 100th. He has written about himself:

A lot has happened since I last wrote

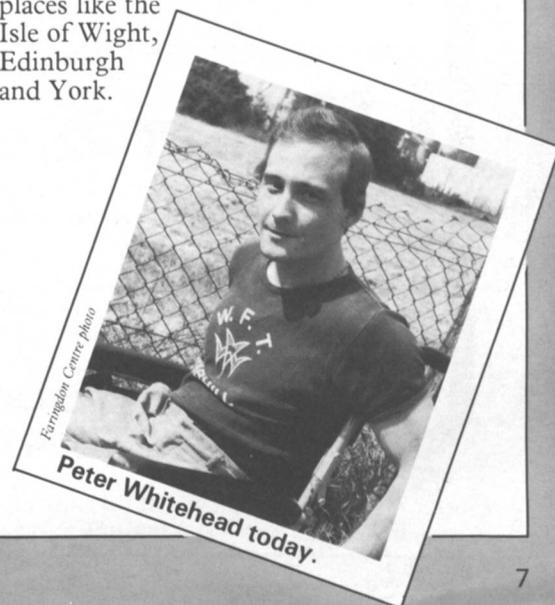
“I was still at school in Kent the last time I wrote back in the summer of 1975. Since then a lot has happened to me.

I left Coney Hill School in July 1979 and went back home to Essex. I was unemployed for eight months, but then I found a job at Remploy.

I started to learn the trade of book-binding, but after five months I found I wasn't working fast enough to keep the job, and I was asked to leave.

In November 1980 I started at the Faringdon Day Centre for the Physically Handicapped and the Elderly, at Harold Hill, Romford. It is a place where we can go for our own pleasure or to do some kind of job such as packing or assembling

In 1982, I started to go with a group of people both able-bodied and physically handicapped. This group decided to form a club — the 3H Club — the Havering Handicapped and Helpers Club. We meet every Tuesday night and we have had many day trips to places like Margate, London and Brighton and have taken in shows in London. The Club has also had weekends sailing and there have been holidays in places like the Isle of Wight, Edinburgh and York.



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Does anybody know saucy Sarah?

THREE-year-old Sarah (right) thinks she's spotted just the right spotted hat!

The Duchess of Kent was enjoying herself with hundreds of youngsters at a clowns' tea party organised by the Variety Club of Great Britain at London's Guildhall in July, when Sarah Karney, who has spina bifida, was caught by the camera in 'mid grab'.

This picture appeared the following day in the Daily Mail.

LINK has tried to trace Sarah but has had no luck. Does any reader know Sarah and where she lives?

Photo: Daily Mail, London.



Local Association Round-up

Bedford & District

MEMBER, Neil McCormack was presented with a Speedwell Supakart as a result of a buffet dance in Kempston. A Grand Draw organised by the Mainline Big Band yielded a further £200 which has been spent on a hand-powered hob cart for 3-year-old Rebecca Ellison.

Blackpool & Fylde

A GROUP of members had such a good holiday at the Maison De Landes Hotel in Jersey that it has been decided to save up for a similar holiday in two years time. At the end of July the group had a sponsored wheelchair push over a distance of 10 miles, helped by the 14th Blackpool Cubs and Scouts. Everyone ended up very wet because of heavy rain, but it was hoped that the total raised would revive everyone's spirits.

Wessex

THREE of the young adult members have recently passed their driving test and now have their own cars. It took some time to find the right cars at a price they could afford, given that the insurance for drivers of their age is high. The three are David Bowsher, who is working for Plessey after completing an electrical wiring course at Queen Elizabeth training College, followed by work experience locally; Paul Sutherland who attends a day centre and is working towards a City and Guilds Certificate, and Lisa Stroud who has just been accepted for a Youth Training Scheme as a secretary in Yeovil, after being at Lord Mayor Treloar College in Alton.

Essex Branch

THE BRANCH is working towards the possibility of

Continued over page



Mark shows the way as Great North Run attracts 25,000 competitors

Mark Tong (above) was first of 25,000 competitors to finish this year's Great North Run. Mark, 15, of Morpeth, who has spina bifida, finished in 77 minutes, 16 seconds.

Although he hadn't done much training for the Run itself, Mark is very fit. He's a member of Tyneside Wanderers' Basketball Team in Gateshead and is one of Britain's fastest ice-sledge racers. He was featured in the March LINK.

Mark was just one of several members of North East ASBAH who took part in the Run. They included our Fieldworker, Sandra Wheatley. Another was Samantha Nicholson (also pictured above). She went on to win a couple of events at Stoke Mandeville shortly after the Run.

The Great North Run was won by Salford Harrier Steve Kenyon in a record equalling time for the course of 62 minutes 44 seconds.

Mark's photo: Newcastle Journal.

Local Association Round-up

Continued from page 9

purchasing and adapting some sort of housing for young adults. The fund-raising committee has been busy with parachute jumps, various stalls at fetes, and its big fete in Hornchurch. It is also planning the annual Halloween Fair. The annual outing this year is to Woburn.

Dudley & Wolverhampton

A DAY out at the Ministry of Transport Road Show at Crowthorne in Berkshire in June for 28 members of the local association was enjoyed, in particular, by the older teenagers who tried out various adapted cars on the special test circuit. Several of the young members are already driving and others are taking lessons.

Staffordshire

THE association is busy making plans to celebrate its 21st birthday next year with a variety of events which will include members of Cannock and Walsall, and Dudley and Wolverhampton associations who were originally part of Staffordshire before forming their own groups.

Leicester

AS PART of this association's determination to be well represented in the region at all levels, one of the Trustees, Mr T. Noon, has recently been appointed to the Leicestershire Health Authority Joint Consultative Committee. This Committee advises health authorities and local authorities on their performance in co-operative activities and on the planning and operation of services.

Bolton & Bury

THE association's swimming club has been restarted and about 20 members go



Ambulance answers the call



Computers ahoy!

DURING Andrew Stephen's long stay in Liverpool Children's Hospital this Summer for an operation on his spine there was a visit from sailors from HMS Sovereign who presented the hospital with two computers for the children's ward. Andrew (above, left) from Barrow-in-Furness, is pictured at the presentation with two members of HMS Sovereign and a young would-be sailor!

Photo: Liverpool Daily Post.

every fortnight to Farnworth Baths. Several members are proving their sporting prowess in other ways — by winning medals at snooker, bowls, darts, etc. Members are also involved with wheelchair dancing.

Choosing what must have been about the only hot day of summer, 32 members had a memorable day out in Southport. Some went shopping, others stayed on the beach, while young

Andrea Mayren decided to go flying with her father for a flip in the skies around the bay. The day ended with an enjoyable meal for all at the Highfield Inn.

Sussex Association

AS LINK is published members of Sussex association, aged 18 plus, are trying their hand at a variety of physical challenges at a special weekend at Hindleap Warren in Ashdown Forest.

THERE'S good reason for looking pleased — and it's all due to the ambulance in the background! It has recently been given to Midland's Association workshop Court Enterprises by Lucas.

Dorothy Artingstall, Chairman of Midlands, writes: "Our workshop has now been open over two years and one of our greatest problems has always been transport. We had an old ambulance given to us by Social Services which limped round Birmingham.

"Imagine our joy when Lucas's said they would like to give us an ambulance. It is wonderful. It comes out of its garage every morning with a smile and gets on with the job of gathering up the young people.

"We have a driver who is very good — from the Manpower Services. He worked for us in a voluntary capacity for 18 months. We applied to MS for a grant for his wages so we might employ him, and they have agreed to pay 20 hours a week."

They are tackling an assault course, climbing wall, rifle shooting, and a night walk. 20 disabled young members, plus able-bodied helpers of the same age are taking part.

Sussex association is trying a new fund-raising idea — a jail break! On September 28, different teams will assemble at Worthing Rugby Football ground in Angmering, Sussex, and on the command 'Ready, steady, go' will 'break out' to see who can get

Local Association Round-up

the furthest in 12 hours, or 24 hours without spending any of their own money. A similar event for another organisation last year had teams getting as far as San Francisco! The teams are sponsored for the number of miles they cover.

Chester and District

DESPITE a very wet day, a good crowd turned up for "It's a Knockout" at the end of June organised by RAF Sealand in aid of Chester Association. It was the second time the camp had organised this competition for Chester. Members are staying close to home for their annual outing. They are off to Chester Zoo which has proved helpful towards the disabled.

Bournemouth

THIS Association has just spent a considerable sum of money re-furnishing its holiday bungalow in Looe in Cornwall. The money was raised by one single large donation, and the bungalow now has new furniture, new colour television — most important in view of this summer's weather — and has been completely re-decorated. The money which was raised from letting the bungalow has recently provided three electric wheelchairs and other items for the members, and should also be enough to pay for a disco. The bungalow has proved a most worthwhile investment — and although Bournemouth's own members don't use it so much now, families from other parts of the country certainly do. This association is hoping its own youngsters will use it for 'independence weekends'.



Donna finds it a chilly business

DONNA Piper (left), aged 16, of Sand Road, Sand Bay, near Weston-super-Mare, enjoyed this chance to try a special sledge for the disabled at Bristol Ice Rink, but found it rather chilly being so close to the ice.

"It was good fun, but unfortunately I started a cold when I got home!" she said.

Donna has spina bifida and was at Bristol rink with her mother Gloria. Donna was asked if she would like to be the first to try this special sledge designed for disabled Bristol athlete Sid Ralfs.

Donna goes to South Bristol College and hopes soon to start at the Star Centre at Cheltenham.

Photo: George Gallop.



It's sun and sea

Members of North East Association relax on board ship and enjoy the sunshine. They are on a weekend trip to Harburg earlier this year.

Chesterfield

AN ACHIEVEMENT Trophy for this year, presented by Chesterfield Association, has been awarded to Robert McDowell, 16, who completed a gruelling half Marathon in his wheelchair at the beginning of the year over undulating roads in Chesterfield. The Award is a

tankard given by the crew of HMS 'Danae' — Chesterfield's adopted ship.

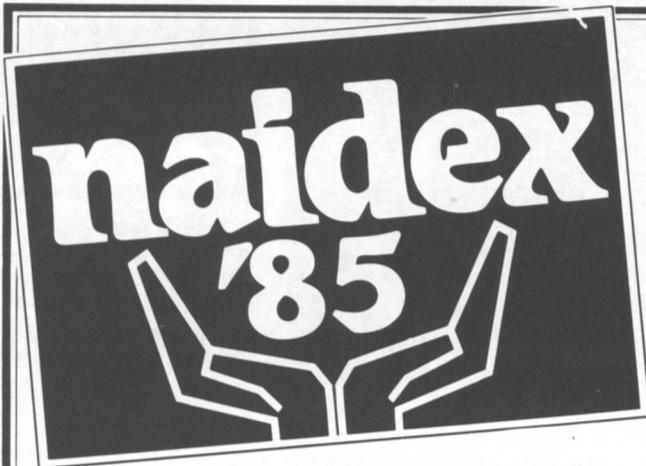
Bristol

BRISTOL and District members are fundraising for the craft workshop as well as to cover usual association expenses. A home produce stall was organised for the

Bristol Harbour Regatta in August, and members made cakes and bottled jam for weeks before. It raised £360. A coach party to Ryde on the Isle of Wight for a day's outing proved very successful despite a wet and blowy start.

Northants

A 'DREAM' FLIGHT with Noel Edmonds in his new helicopter became a reality for 20-year-old Sarah Mann, a member of this local association earlier in the year. Sarah, who has spina bifida, describes herself as Noel's 'No. 1 fan', and the special afternoon flight above the Northants' countryside, taking off from Sywell airfield, was Noel's way of saying thanks to Sarah for her support. Sarah was joined on the flight by her mother, Jean and brother Louis, while dad stayed safely on terra firma!



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Don't 'display' our children on the streets

I for one have an ideal for my child which really is, I believe, to be quite progressive. I want, and aim for my child to be treated as though her calipers are invisible! And before you think I'm just running away from reality or from my problems I don't believe that is true.

I have ambitions and ideals for my child in spite of the accident found at birth (she has the label of spina bifida). I believe that it is important that my daughter grows up to be independent, lively, sociable and fully integrated into our society. Remember the International Year of the Disabled when we fought for public awareness so the disabled could be accepted as human beings! I believe for this aim to be realised all of us must begin on our own doorsteps. Sometimes I feel our cause is likened to that of the suffragettes who fought so emotionally for the acceptance and now equality of women . . . that special breed!

Are these aims fulfilled when we display our disabled on the streets shaking our tins and asking for the money? Think for a moment of the emotions of the giver and receiver. I am reminded of the time whilst visiting a major city in the western world when I came across a well dressed gentleman sitting on the pavement exposing an artificial leg and waving a hat to passers-by. I felt outraged that our fellow human beings could be so degraded.

Are we not doing our loved ones a disservice by displaying them on the streets and enhancing the present way our society thinks about and treats our disabled? Are we not making the disabled different? If the disabled want to be fully integrated into our society and require people's prejudices to be eradicated then let's encourage as normal an existence as possible. If we mix our children into society they can enlighten the masses by their very existence. If our children learn to be self-supporting they will enjoy the respect and affection of everybody; what better ambassadors for our cause.

Please let us not display our children on the streets; surely there must be a more appropriate way of gaining funds.

Geraldine Walsh,
New Eltham,
London.

Letters

It's just laughable . . .

I am writing with great annoyance at the letter printed in the July/August 1985 by Paul Cooper.

He says that cinemas' are free for disabled people. This is utterly preposterous. At our local cinema, entry is impossible because of the stairs.

Disabled people have to fight hard to get a place in the world today. Charities such as ASBAH are not just here to hand out money. They are here to give advice and help to people in wheelchairs.

I attend a grammar school and not once have I been able to go on a school holiday with my form because of the "lack of facilities". It's just laughable really. Your letter, Paul, angers me because it is so insensitive — boats, planes, trains, buses, coaches, swimming baths, cinemas, hotels, caravans (some — not all), office buildings are nearly always impossible to enter, and you say that we have to gain the respect of able-bodied people. Are we not people? Why do we need to gain the respect of anyone?

Yes, I do want to be treated as an equal. Next time you go to a cinema, Paul, ask how many disabled people come to your cinema? Then you will find out that people like you should think before writing an article like this.

Marcia Summons (14),
Urmston, Manchester

Happy Birthday to LINK!

Happy birthday to LINK from all the members of Bristol Association. We look forward to reading the next 100.

Sheila Egan,
Bristol Association

I would like to send my congratulations to LINK for its 100th edition. We must have 99 copies here as we've taken it since it started!

T. A. Rodaway,
Haywards Heath,
W. Sussex

No more punctures!

A COLD rainy day, your're tired and hungry, and to cap it all, you get a puncture in your wheelchair tyre! It's the stuff that nightmares are made of, isn't it. . . .

We can't do much about the cold, the rain or the hunger, but we can help by introducing you to a new product that is designed to eliminate the possibility of a puncture or leaking valve in wheelchair tyres. . . .

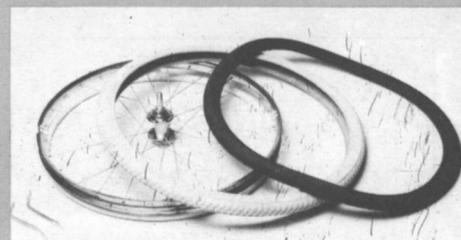
Called Flexel it is a new special resilient cellular infill which replaces the conventional inner tube. It has been developed, and is being produced under licence by Vitamol.

Based on natural rubber, it is totally unaffected by punctures. It makes the wheelchair a little heavier and gives a slightly harder ride, but can be a real benefit where punctures are proving to be a significant problem.

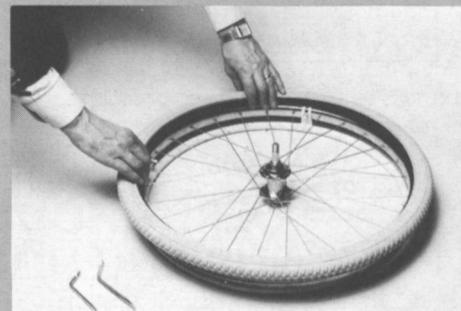
Flexel is available in two forms — moulded directly into rim and tyre, or as a separate infill.

It is available through the DHSS Wheelchair Service so contact your nearest A.L.A.C.

Any problems or queries should go direct to: Vitamol Division, British Vita PLC, Middleton, Manchester, M24 2DB. Tel: 061 643 1133.



● Wheel, tyre and Flexel infill before assembly. Flexel occupies the complete space between tyre and rim. Moisten Flexel with soapy solution to ease fitting. The only other things you need are conventional cycle tyre levers.



● Fit one bead of the tyre over the rim and insert the Flexel infill.

● Lever the infill into position in the rim. Then slight hand pressure all round will confirm that it is seated correctly.

● To complete, simply lever the remaining tyre bead onto the rim. The wheel is now punctureproof and ready for use.

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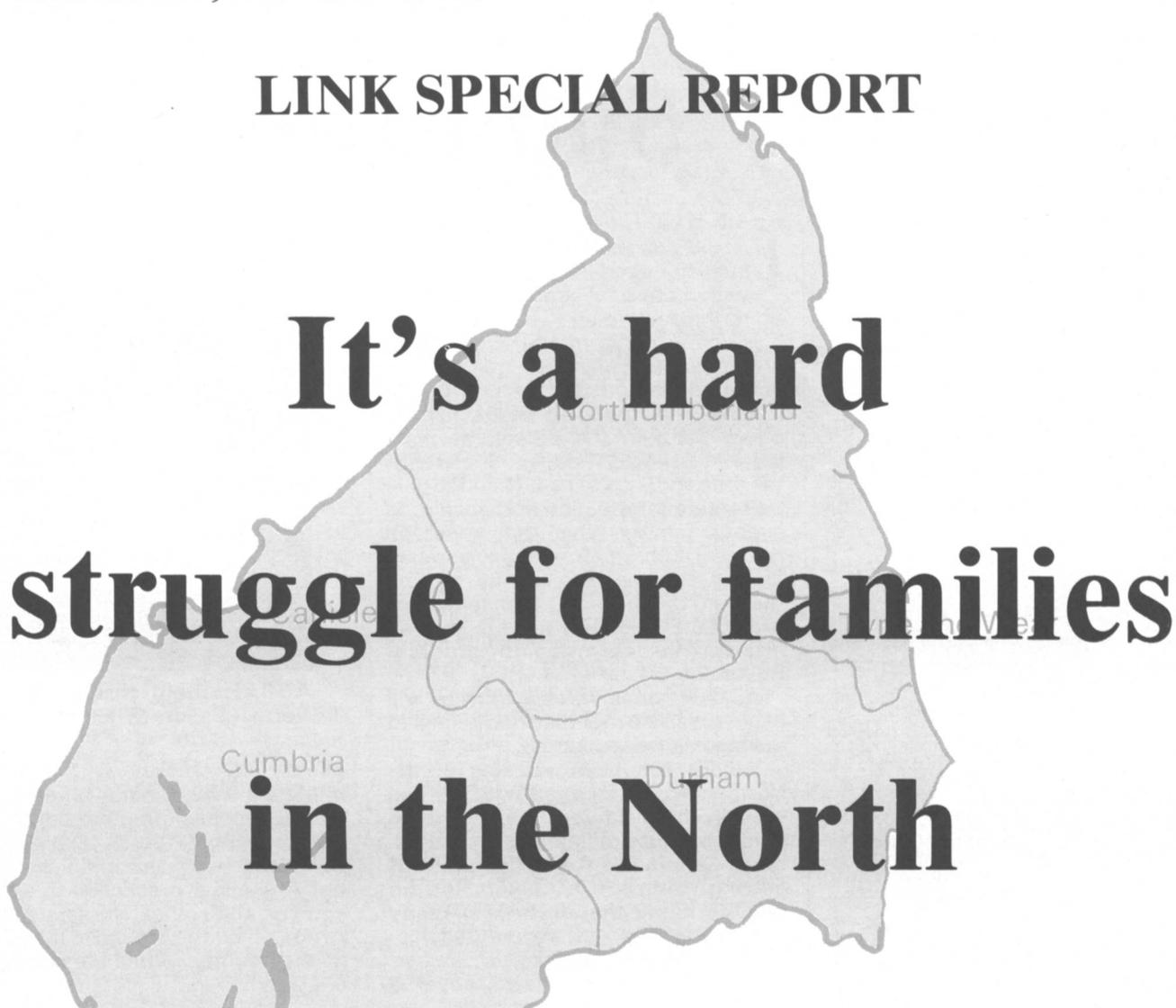
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10 WHITEFIELD TERRACE
GREENBANK, PLYMOUTH

LINK Editor, Sue Gearing, spent three days with ASBAH fieldworker, Sandra Wheatley, looking at some of the special problems faced by people with spina bifida and hydrocephalus and their families in the North of England.

Sandra's 'patch' is very extensive, stretching from Carlisle and Barrow-in-Furness in the West to Morpeth and Darlington in the East — in other words the whole of Northumberland, Durham and Cumbria.

LINK SPECIAL REPORT



It's a hard struggle for families in the North

IT's an unfortunate fact of life that it does matter where you live in Britain if you have spina bifida and hydrocephalus and are looking for good medical treatment, financial help, suitable aids, and a stimulating education.

Many families in the North whom I met, particularly in the North West, have a very hard struggle indeed and receive little or no help or encouragement from anyone.

It's grossly unfair, and it's easy to understand how apathy can set in. It takes a very special kind of family to fight a system that doesn't seem to give a jot.

Adaptations

I met a family in the North West who are having no success in getting the local authority to help with adaptations or aids

to the house that they have just managed to buy. They admit that they bought the house having been advised against it by the local authority, but that doesn't alter the fact that they now face substantial problems.

The teenage son is severely disabled with spina bifida and hydrocephalus and has just returned home after a long period in hospital. He is having to sleep on a mattress on the kitchen floor, wash in the kitchen, or be carried upstairs to the bathroom.

In fact, I have since heard that the situation became so chronic that the Chief Building Control Officer has insisted that adaptations be carried out, so as Sandra Wheatley said to me: "Let's hope things are moving."

They are a low income family already trying to cope with a number of stresses,

so they really do need a helping hand.

Mum didn't have enough money to afford the cost of travel to the hospital 70 miles away where her son underwent a number of long and difficult operations, nor the cost of accommodation so she could stay there to be near him. The family recently applied to ASBAH, through Sandra Wheatley, for a travel grant and fortunately ASBAH is going to help.

Another family — this time in the North East — say they had managed to get a stairlift fitted by the local authority ten years ago. But it no longer works properly — it needs alterations and repair because obviously the spina bifida son has grown much bigger in the intervening years. The authority say that

Continued over page

LINK Special Report

Sandra finds 500 families

the family must pay half the cost.

I talked to another family who are still having to lift their teenage daughter — who has spina bifida and hydrocephalus — upstairs to the bathroom despite the fact that a new bedroom and shower room extension was put in by the local authority and ostensibly completed over 13 months ago. The plumbing wasn't properly fitted or connected, and consequently there's virtually no heating and no hot water. According to the family repeated representations to the council have met with no success.

Yet another family in the North West told me of a two year wait for a path and ramp so that their son who is in a wheelchair could safely get in and out of the house. When it was finally completed, the path proved to be difficult to negotiate because of a number of sharp bends. There appeared to be no reason why the path couldn't have gone more-or-less straight up to the door.

Adaptations and equipment

Kay, a young mother in a wheelchair with spina bifida and living on her own with her 4-year old daughter feels that she is being treated as a second-class citizen.

She had already had problems with the social services department over alterations to her bathroom. The siting of the door at the wrong end of the bathroom meant that she could barely squeeze by the lavatory in her wheelchair in order to get to the rest of the bathroom. Eventually the council came and moved the door to the other end as she had originally planned.

It was necessary for her to have cooking facilities installed at wheelchair height. The social services applied to ASBAH for a grant for a new cooker and hob, but before ASBAH had a chance to reply the social services decided to act off their own bat and buy a second-hand cooker which Kay had seen advertised locally. She had expressly asked for a grill because she suffered with a gastric ulcer which meant that grilling was her most suitable method of cooking. When the representative from the social services went to see the advertised cooker she reported back that it was ideal, so the mum agreed to put a small amount of her own money towards the cooker, and a hob.

The cooker arrived in a filthy state and had no grill. The young mum cleaned the cooker herself and felt that she had little alternative but to go ahead and have

It is difficult for families already very busy and tired from having to cope with a physical handicap, to stand up to the system on their own.

In many areas in the North there aren't enough families to form a strong, united group.

ASBAH is trying to be of help by being there in the person of fieldworker, Sandra Wheatley. She lives in the area and tries to be on hand to give up-to-date information and advice, to support families when they approach the local authority for help, to assist in finding suitable aids, or by putting them in touch with a consultant or clinic if they feel they need to seek an alternative opinion on medical treatment.

ASBAH hopes that the families will begin to realise that they don't have to manage alone any longer.

Sandra has been working in the Northern region for a year. ASBAH had virtually no fieldwork support there before because of financial considerations. Sandra has the difficult task of getting round the region letting families know that ASBAH is ready and able to help with support, advice, grants, or just by listening.

In the past year she has discovered



ASBAH fieldworker in the North — Sandra Wheatley.

about 500 families with a son or daughter with spina bifida and/or hydrocephalus. Undoubtedly, there are many more. Clearly an area of this size does need another fieldworker, but ASBAH at present hasn't the resources and so fieldworkers continue to be thin on the ground in many parts of the country. Some areas have none at all.

it fitted. She had worked out where she wanted the cooker and separate hob fitted, but somehow or other this seemed to be forgotten when the fitting took place. As a result she found that the appliances weren't where she had expected them and she was left with very little usable work surfaces. There ensued correspondence and phone calls — with ASBAH help — and eventually the social services decided 'to abandon' this cooker.

The appliances were disconnected leaving her with no cooking facilities at all for several weeks, during which time she had to wheel herself in all weathers round to her mother's taking her young daughter whenever they wanted a hot meal.

Then they fell sick and couldn't get out. Social services were unable to help with an emergency cooker, so Sandra Wheatley loaded a Baby Belling into her car and drove from her home near Darlington right across country so that mum and daughter had some means of cooking for themselves.

The situation at present is that the social services have agreed to try and get a new cooker, and have applied to ASBAH for a grant towards this. Any money raised from the sale of the old cooker will be put towards the new one. Kay is keeping her fingers crossed!

Education

Disabled people are trying hard to be accepted as equals and it's a blow to the

LINK Special Report

confidence and optimism of a teenager with spina bifida when she is more-or-less barred from going to the local upper school with the friends whom she has been with since primary school age.

"Yes" she could go to the neighbourhood school, but she would miss out on a good deal of the curriculum (and a part of the curriculum that interests her the most) because the classes are held on the 2nd and 3rd floors which she can't reach.

With Sandra Wheatley and Lisa's mother I visited the Director of Education for the area concerned to discuss the matter with him at the beautiful new County hall set in landscape grounds.

We walked through automatic doors, past a pretty inner courtyard with plants and an ornamental pond, to a comfortable office, and it was difficult not to contrast these surroundings with the fact that we were told that the authority wasn't prepared to consider spending money on adapting the neighbourhood school for Lisa — and no doubt for other physically handicapped young people who might have wished to attend in future. We were told there was a 'designated' school a few miles away, deemed to be architecturally more suitable for physically handicapped pupils, although as yet no adaptation have been carried out.

Yes, it would seem she would get a good education there, and it is to the credit of the heads of both schools that they are trying to ease the situation. The designated school has said that Lisa's special friend can attend their school youth club, and the same invitation has been extended to Lisa for the youth club at the neighbourhood school.

But Lisa is trying hard not to be different from her friends and doesn't want to be distanced by going to another school.

What was a very difficult situation was exacerbated when Lisa — who by this time had more-or-less decided that she would have to go to the designated school — received a letter saying that the neighbourhood school was looking forward to receiving her. Had the authorities made special arrangements for her after all? No — it was only the standard letter sent to everyone in her class. It was a regrettable mistake, and Lisa was still only going to get the benefit of a full school curriculum if she went to the designated school.

Clearly it isn't feasible for every school in the country to be adapted at great

expense, but more flexibility, understanding and general caring would be welcomed and would go a long way towards forging a good relationship between education authorities and 'disabled families' instead of widening the gap.

A number of families I spoke with in the North West complained at the lack of good special school facilities, and of the very limited hospital facilities in the area. Going to a spina bifida clinic means a journey across to Newcastle or down to Liverpool.

It is amazing that against all the odds individuals do manage to fight... people like the Smiths of Carlisle, where facilities are notably lacking, have managed to get together a group of parents with handicapped youngsters (Carlisle Handicapped Children's Society) which organises social events, including a holiday to Lourdes every two years; people like those who run the PHAB club in Barrow where social activities for those with spina bifida and hydrocephalus were more-or-less non-existent until it began; people like the mother who fought to get the help of a consultant in London for a major special operation so that her teenage son could cope with the problems of incontinence and be able to go to the ordinary local school with his friends and his brother.

The North East

Families in parts of the North East appear to fare better, with Newcastle as the 'mecca'. The city is well-known for its facilities for the disabled. Shopping is easy. There's the accessible metro, a good dial-a-ride scheme in Newcastle and in Sunderland (Transfare), good special schools — Pendower in Newcastle which has a multi-disciplinary team to cope with all the children's needs, and Barbara Priestman in Sunderland which is starting a special independence training course for its pupils over 16 to get them well and truly familiar with every day life. Already some of the older pupils come to school each day by public transport. There's a spina bifida clinic in Newcastle, a catheter clinic and a young adult clinic so that care doesn't come to an abrupt halt at 16.

The Council for the Disabled in Newcastle has recently opened a splendid new £270,000 Dene Centre which houses the aids and appliances centre, and where assessments and conferences

can take place. This is also where the Wheelchair and Young Adult Clinics now meet.

But while opportunities and facilities may be good if you live in Newcastle itself, it appears to be not so true if you live just a couple of miles outside the City of Newcastle. I heard evidence that facilities don't extend outside the city itself.

There are active local ASBAH's in the North East area who busily work away to raise money to pay for some brief respite from the daily struggle. They arrange various social outings — Sunderland members are off to America this Autumn, and those around Newcastle (the North East Association) have enjoyed a trip to Hamburg this year.

All over the North families seem ignorant of their rights and the benefits to which they are entitled, and stories of incompetence and disinterest, and the social services departments having no money to help are commonplace.

The Poverty trap

These stories may be true in all parts of the country and be familiar to many LINK readers, but they strike the hardest in areas like the North where people are gripped by unemployment, and are caught in 'the poverty trap'. The average Northerner has far less money to spend than his counterpart down South.

Hopefully ASBAH's presence — in the person of Sandra Wheatley who is backed up by National Office — will start to make a difference, and give the families there the security of knowing that they do have an organisation on their side. ASBAH does care and does have a good deal of expertise, and knowledge. What's more it has a voice.

**Sue Gearing
Editor**

ASBAH sent this article to the appropriate Director of Social Services prior to publication.

He has asked LINK to record his great concern at the situation highlighted in the report, and says he will undertake a thorough investigation.

He hopes to be in a position to report back in the next issue of LINK.

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Report on lifestyles paints grim picture

A THOROUGH examination of the Unmet Needs of Handicapped Young Adults has been undertaken by the Paediatric Research Unit of the Royal Devon and Exeter Hospital. The Study, conducted in Exeter City and the surrounding towns and villages considered all disabilities, mental and physical.

The evidence produced illustrates graphically the consequences of being considered and treated as disabled in our society. In almost every aspect of life the young disabled adults were worse off than the group of 150 able-bodied young people (aged 16-25) with whom they were compared.

A strong theme of the report is that their problems and unmet needs stemmed primarily from the low expectations of them, and disparate, deficient services made available to them throughout their lives, rather than the actual physical impairment.

A total of 803 interviews concerning 383 individuals were undertaken with the young adults, parents and various professionals involved. 2160 unmet needs, current and future were identified amongst those with disabilities. On average each person had 95, which covered work, education, training, transport, housing, health and social life.

Unoccupied

For instance, those with disabilities were more than twice as likely to be unoccupied during the day, and 48% were in some type of 'work alternative', yet the figure for the comparison group was only 14%. In addition 40% had no way of occupying their day. Socially the picture is also grim. Three times as many of the group with handicaps never went out in the week before they were interviewed, and 30% did not go out with

friends. This contrasts starkly with a figure of 3% for the young people in the comparison group.

The reasons for this were varied, but included difficulties with transport, inaccessible buildings, and very significant lack of self-confidence and self-esteem. All this combined to produce great isolation from their peers.

Although it is stressed that those in the study were all very different as individuals, there were many problems in common; lots were unskilled in personal self care, had little knowledge of their disability, and 70% had basic educational difficulties. Once again problems were rooted in their treatment, not in the actual physical impairment.

The report states: "normally the young adult gradually learns to take control of his own life. He meets new people, shares new experiences, takes responsibility and chooses the type of life he wants. In the process he learns to moderate certain kinds of behaviour so that he is accepted by each group that he meets". For many featured in the study, such opportunities to develop are absent.

As a result it is recommended that all concerned raise their expectations of the young people and combine to make sure that more choices in terms of occupation, housing and social life are developed.

The whole person

One of the commendable features of the report is that it is not merely a depressing

account of unmet needs. It also suggests how in East Devon vast improvements could be made—recommendations which could be applied to all areas of the country. Instead of each service, i.e. Health, Education, Housing, Employment and Social Services, dealing with people in a very separate discreet manner (if at all!) they should collectively deal with "the whole person", so that all efforts on a long-term basis are made to ensure that the young people develop to their full capacity in order to exercise choice and control over their own future lifestyles.

There are many interesting ideas and suggestions for action in the conclusion, which considers all the areas in the study. The researchers gathered so much information that they intend to produce reports on each individual subject along with further detailed recommendations, which is certainly something to be welcomed. This is only 'the First Report'. As they say in their concluding paragraph: "We would not wish anyone to think this is our last word!"

On the basis of the findings action to improve services in East Devon is being taken. For those concerned about the choices and opportunities for the young handicapped adults in their areas and who wish to see changes of a positive nature then this easily-read report is invaluable.

- ★ *Deficient Services*
- ★ *Low expectations*
- ★ *Lack of self-esteem*
- ★ *Isolation*
- ★ *Educational problems*
- ★ *Transport & access problems*

The Director of the Paediatric Research Unit is Prof. Frederic Brimblecombe, CBE., and the Project Co-ordinators — Mrs Diana Kuh and Dr Ronald Smith.

ASBAH has taken a close interest in the production of this valuable report, and hopes that the findings will be widely read and acted upon.

You can obtain a copy from The Paediatric Research Unit, The Royal Devon & Exeter Hospital (Heavitree), Exeter EX1 2ED. Price £2.00.

Siobhan Rowe,
ASBAH's
Accommodation &
Development Officer.

I WAS first introduced to intermittent catheterisation as a possible solution to my incontinence when I was about 13. This new technique had been successful with a number of my friends at school in Darlington, but I proved to be rather an awkward case for a number of reasons.

Perhaps one of the greatest reasons for my problems with using the catheter was that unlike many of the pupils at school who used the catheter, I did have some degree of feeling around the urethra. This made me tend to tense my bladder muscles when the urethra was approached and therefore the tube could not be inserted.

At a trial to see whether I was suitable for intermittent catheterisation I pushed the catheter out with my muscles. It was decided that for the moment I should abandon the idea of using a catheter. Back to my pads then.

The prospect of always having to wear pads and smelling badly is not one which a teenager relishes, so a few years after the initial trial, encouraged by my surgeon, and my parents, I decided to give intermittent catheterisation another try and to attend clinics to learn the techniques.

Once again I encountered problems with the catheter, the initial problem of my muscles tensing and also problems with my own attitude. While I immediately learnt the procedure of catheterisation — wash your hands, wash around the urethra with Savlodil, dip the catheter into KY Jelly, insert it into the urethra, etc. — I could not actually get it into the urethra.

The usual method of teaching girls the correct place to put the catheter is by showing them the urethra and the surrounding area in a mirror. However, I, being naturally a little squeamish, found the idea of looking in a mirror very off-putting; I would just have to find the correct place by another method.

Having some feeling I could tell when I had reached the urethra, but doing things by feel was rather painful since at first I kept aiming at my vagina and ended up feeling rather sore. Eventually I managed to catheterise myself lying down (I always seemed to sit on my urethra whenever I tried to manage catheterising myself sitting up) but for every time I was successful there were three when I was not.

It seemed that the nurse who ran the clinics, whose success rate at teaching youngsters how to use a catheter is remarkable, had finally met with a failure. Considering the ages of some of her successes (around six, if not younger) I, at 16, felt rather ashamed of myself for failing.

After leaving school I went away to

FOR SOME people intermittent catheterisation has proved a practical answer to problems of incontinence. But it is not without its problems. Here, Susan, a student on a degree course at a polytechnic college, tells her own personal story of the determination which was required to master the techniques involved. It was not easy. It took a great deal of time. But all the effort has proved well worthwhile. The story should encourage others.

INTERMITTENT CATHETERISATION

Try, try and try again — it's worth it

college in Coventry. There was only a short break between lessons and the Matron and Care-staff had to attend to students who were in far greater need of help than I was. Therefore, for convenience I was given an indwelling catheter with a drainage bag. This was quick and easy to empty and at first there were no problems.

However, when I came home towards the end of the year problems started to occur. Indwelling catheters are expected to last four to six weeks but my catheter was nearly always blocked after a week so the urine just bypassed. I had urine infections and eventually I decided to try intermittent catheterisation again.

Shortly after this conversion I had a bladder stone which was the result of calcium deposits accumulating due, probably, to spending a year on the indwelling catheter which is really better as just a temporary expedient.

I have now been back on intermittent catheterisation for two years and am fairly competent in catheterising myself lying down thanks to persistence and the great patience of my mother and the nurse. Managing the catheter sitting up is still rather a problem due to balancing and getting into the correct position but I am still practising and have had some success. Obviously I would be able to go out for longer periods if I could manage sitting up. A number of public toilets hardly can accommodate a wheelchair let alone allow a person to lie down on the floor.

Intermittent catheterisation has largely been responsible for my being able to be integrated into a college for able-bodied students and to do my "A"

levels without having to feel embarrassed over being wet. Day and night now I am nearly always dry. Fortunately I also received a good deal of consideration from the college. The Principal allowed me to use the rest room for catheterising myself and no fuss was ever made if I needed to come out of class.

No system is ever 100% infallible. I do still get infections occasionally which can make me wet and the three hour guideline for catheterisation does not seem that applicable to me. Sometimes I go for four hours or more and sometimes less than two hours. Often when going out I wear a pad just in case I get into difficulties but intermittent catheterisation has made me more confident to go out and mix with people. It has also made me more independent than having a catheter that was forever blocking.

I would advise anyone who is thinking about intermittent catheterisation but has doubts to give it a try. There may be problems at first but with a bit of practise you will overcome them. I don't think there is any one way of learning how to catheterise yourself as I've largely been an exception to any rules that might have been made. For instance, since I do have some feeling I find it easier and more comfortable to use the longer and more flexible male catheter rather than the female one which is somewhat rigid. So please try intermittent catheterisation, I'm sure you will find it an advantage.

Editor's note: Since this article was written Susan has made further progress. She is now able to perform intermittent catheterisation on the toilet.

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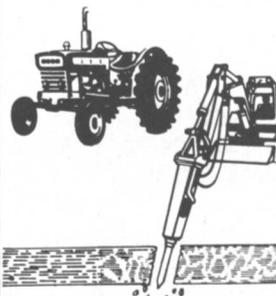
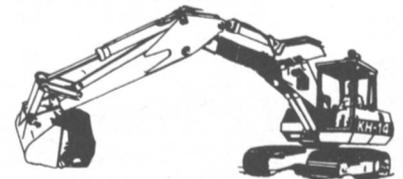
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● **THE STACKPOLE** holiday Adventure Centre recently opened its second phase — a group house available for disabled people, their families and friends.

The Trust is made up of six charities, including ASBAH. One of the Vice-Presidents is the conductor, Jeffrey Tate.

The Adventure Centre, surrounded by beautiful National Trust country on the south coast of Wales, is an ideal place for a comfortable, self-catering holiday.

Five family cottages were tastefully modernised and furnished and made suitable for holidaymakers in wheelchairs during the first phase.

There is complete wheelchair access throughout the whole project and a really high standard of furnishings and equipment to make the holiday go smoothly.

Letting charges range from £55 to £95 per week for the cottages, which accommodate six people, and £15 per person for groups.

Details: Mrs A. M. S. Jones, Reaches Riant, Lawrenny, Nr. Kilgetty, Dyfed, South Wales, SA6 0PP. Tel: 06467 601.

● **THE WINGED Fellowship Trust** has launched a £1.9 million appeal for 'Operation Sandpipers'.

The intention is to build a specially designed holiday centre in the North West of England at Southport on Merseyside.

'Sandpipers' will provide accommodation for 36 guests in double and single rooms,

Newslines NEWSLINES Newslines



The President of the Stackpole Trust, Michael Aspel at the opening of the Holiday Adventure Centre, with John Thorne, the Chairman, and Jason (right) and Darren.

and a heated swimming pool will be included among the facilities. The centre will overlook the marine lake and

be within easy walking distance of the town centre. Southport is a good centre for visiting Blackpool, the Lake

District, North Wales, Cheshire, Manchester and Liverpool.

● **CONCERN** was recently expressed to Sir Keith Joseph about the reduction in services for disabled students at the Open University. Sir Keith has now replied that the visiting committee which examined the OU's plans for reductions in grant had specifically recommended that services for disabled students should be protected.

The situation is to be kept under review, but it seems that services for disabled students will not be cut any further for the present.

● **THE OFFICE** of Population Censuses and Surveys has been asked by the DHSS to conduct a survey into disability amongst children, probably in October and November this year. Many households will be receiving through the post an initial questionnaire.

To allay the fears that anyone may have about this survey, it may help to know that OPCS is a separate government department from the DHSS and has undertaken that "the names and addresses of people who take part in our survey are held in strict confidence. OPCS do not give them to any other Government Department, to the press or to members of the public...".

OPCS has already carried out one survey recently into health and disability, and next year will see a separate survey on disabled people in residential care.

MEETING POINTS

ASBAH STUDY DAY
Pilgrim Hospital, Boston,
Lincs. Tuesday, October 22.

THIS IS a Study Day for parents and professionals. Speakers will include: Dr Roger Bayston on Causes and Treatment of Hydrocephalus; Leonie Holgate on Learning Difficulties Associated with Hydrocephalus; John Wright from Boston College of Further Educa-

tion; plus speakers from National ASBAH on Work Experience, and Sheltered Employment Schemes, and Housing.

Details: Denise Dunning, National Office, ASBAH.

DRIVING ABILITY COURSE

Five Oaks, Ilkley, West Yorkshire. November 4-17.

THIS IS an intensive two-

week training course for people who have already been assessed for driving ability and are classed as 'borderline'. At the end of the course the assessors will give the students a good idea of whether they are suitable to drive, how long it would take to learn and the likely cost of lessons. The total cost of lessons, assessment, and full board for the fortnight will be about £300.

If you are interested please contact the Mobility Centre, Banstead Place, Park Road, Banstead, Surrey SM7 3EE. Tel: Burgh Heath 51674. (They may arrange for you to have an initial assessment, if you have not already had one.) Or telephone Five Oaks 0934 609468.

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FIRST they said they couldn't hire me because I didn't have any work experience. So I proceeded over the summer months and spare moments during university studies to gain this ever precious "experience".

I volunteered in various hospitals and schools tutoring physically handicapped children and adults with speech impairments. From this rewarding and yet very time-consuming endeavour I became quite acquainted with numerous speech disorders and the social stigma associated with such communication problems.

Despite all this dedicated volunteer work and a four year Honours B.A. in English and Psychology that was so painstakingly obtained with hopes of following up with a Masters in Speech Therapy, the job search just dragged on for three and a half months post graduation. As the days stretched into weeks, and then into months, the job outlook seemed futile, and depression set in.

Realising I already had three strikes against me: ● I'm a female, ● I'm handicapped, and ● I hadn't had any previous work experience (just volunteer work), hopelessness seemed imminent. With every interview I had gone through I was either physically incapable of doing certain tasks, didn't have a Masters degree, or had no office work experience.

Fine. Feeling quite dejected by the whole ordeal, I finally stooped to accept a minimum wage job offered by the government that was aimed at youths 15 to 24 years of age who hadn't been able to find work within the past three months. This particular job was specifically geared towards handicapped employment. **Perfect,** I thought at first.

Entering into the job with the impression received in the interview, that I would be doing research and travel outside the city, I accepted the minimum wage and no benefits component with not too much protest. My naive smoke-screened view of the job gradually cleared, and I became quite aware of the condescending treatment I was being given.

Before long I simply had to stand up and express my dissatisfaction with my supervisor's lack of respect for my capabilities, lack of supervision, and complete misrepresentation of the job description.

After doing some convincing of my abilities, I took up the task of devising a library catalogue system that would integrate books from two different departments. The job was done within five months which also included labelling and shelving all the books, typing up all the index cards and constructing a library log which kept



In International Youth Year, Link continues its series of personal stories written by young people around the world. Here Carolyn Jagger from Willowdale, Ontario in Canada tells of her early and disappointing experience in the world of work. It may have been very disappointing but Carolyn comes out fighting. . . .

Put on the gloves of self-esteem and confidence

track of the in and out-take of the books.

The only help I received was in shelving the books and carrying them down from one floor to the next.

In addition to this major endeavour, I had other minor office duties to attend to, but none could be classified as "real" research. All the time I had been working there, in spite of setting up a whole library for them, I was still treated with little respect.

So, after seven and a half months, I decided to take another contract job which again is subsidised by the government with minimum wage. However, unlike the previous job, all other colleagues are handicapped in some way or another. Although I am not partial to either handicapped or non handicapped employers, I am glad to say that my present handicapped employer is a very congenial boss.

It is an ironic situation when you

realize that a non handicapped employer who is supposed to promote "affirmative action for the handicapped" has no idea what the term truly signifies. The only way to deal with this sort of discrimination is to face it full force with invulnerable gloves of self-esteem and self-confidence.

If you successfully develop these attributes your physical incapacities should in no way determine your qualifications or success on the job.

The degree of spina bifida that I have only limits me from chasing after small children or carrying heavy loads, neither of which I have any yearning to do. And of course, a washroom within reasonable proximity is all I really require out of sheer necessity.

I walk with crutches and below knee braces, and will always climb the stairs in the hope of losing weight.

Thus, my two greatest obstacles in life are food and water: necessities of life and yet detriments when they metabolize in my body. Fortunately I can consciously control my weight, but my bladder is unharnessable. Like many people with spina bifida, I have a neurogenic bladder. So in actuality bladder control is my only detriment.

Whether I am working or on a date, that will always be a problem, but not an unsurmountable one. And certainly it has absolutely nothing to do with my qualifications or capabilities for employment.

There are many other people with spina bifida, however, who manoeuvre themselves in wheelchairs. They, of course, have two pertinent obstacles: stairs and non accessible bathrooms.

In Canada more and more architects are building their edifices with barrier free design in mind. But if these two physical barriers were removed from every building, the employee with spina bifida would have only half the battle of equality beaten. To make us completely equal employees, we would have to be given equal respect and, of course, equal pay.

My employment experience is not unique. Other handicapped employees are working under similar conditions. I hope recounting my story will encourage those others to develop a sense of self respect, strong enough to deal courageously and confidently with their own situations.

by Carolyn Jagger

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THE Disablement Income Group was the first organisation in Britain to be concerned about the financial consequences of disability. When DIG started in 1965 disabled people, unable to work, looked forward to a lifetime on inadequate and means-tested supplementary benefit.

DIG promoted the introduction of several benefits: attendance allowance, invalidity pension, and a non-contributory pension. DIG also played a leading role in securing a host of other improvements in the social security system, including the recognition of the position of disabled married women. Over one million disabled people now receive basic benefits which were not available prior to our existence.

All this has certainly helped improve the quality of life for disabled people but many still suffer real hardship by simply not having enough money to live on.

Essential Costs

Disabled people inevitably find daily living costs more: they need extra heat; they are unable to shop around and need to buy convenience foods; they require help in the home and special aids and appliances; their disability may result in extra laundry and wear and tear. Yet there is no allowance, such as DIG advocates, to help meet essential costs like these, at least not for disabled people not covered by the industrial injuries or war pensions schemes.

Such a benefit — disablement benefit — exists for people injured at work or in the armed forces. DIG wants to see the disablement benefit made available to 'civilian' disabled people. It is unfair that the social security system should be based on cause of disability, yet it has always been the case that someone disabled at work is much better off than someone with an identical disability caused under other circumstances.

Twenty per cent of their needs

Some extra costs are, at the moment, for those entitled, covered by the 'additional requirements' of the supplementary benefit scheme. These can amount to as much as 20% of a disabled person's supplementary benefit.

Additional requirements will be

THE Disablement Income Group is in its 20th anniversary year, but it sees little cause for celebration. Despite the fact that more than a million people have cause to be thankful for the progress of the past 20 years, PAULINE THOMPSON, DIG's General Secretary argues that injustice still abounds, and, what is more . . .

Many just don't have enough money to live on.

abolished as a result of the Fowler Review. DIG is very concerned that, in the absence of a scheme specially devised for disabled people, their only source of help with essential costs will disappear. The proposed 'premium' for disabled people to be paid with the new income support scheme, which replaces supplementary benefit, is unlikely to be high enough to compensate for the loss of additional requirements.

DIG is strongly urging the retention of additional payments in order to safeguard the interests of disabled people.

Sick or fit?

In spite of the significant developments in income maintenance benefits to replace lost earnings the system may be described as 'sick or fit'. Invalidity benefit brings with it a 'therapeutic earnings limit', which, if exceeded, results in total loss of benefit. There is a need for a flexible invalidity benefit which complements low or part-time earnings during rehabilitation and continues indefinitely if only a limited degree of rehabilitation can be achieved.

Britain would do well to take account of some of the social security systems of other European countries which provide a partial incapacity benefit.

Penalising young disabled people

The national insurance contributions test determines eligibility for invalidity



Pauline Thompson
General Secretary

benefit. Those failing the test, generally young people disabled from childhood, have instead to claim severe disablement allowance, paid at 63% of the basic contributory pension. They seldom have significant other income so they are forced to claim supplementary benefit, which is not a satisfactory basis for dealing with long-term loss of earnings. Income maintenance benefits should be paid at the same, higher rate of invalidity benefit.

Eligibility for severe disablement allowance is determined by an incapacity for work test and a degree of disability test. Anyone failing to establish 80% disability cannot receive it. Only those under the age of 20 claim on the grounds of incapacity for work alone.

Yet invalidity benefit has no such double test: a claimant has simply to be found incapable of work. It is logical and fair that this single criterion should apply also to severe disablement allowance.

Mr Fowler takes our cake

1985 is DIG's 20th Anniversary year. There is, however, little to celebrate. Mr Fowler has warned that we cannot have our cake and eat it and DIG is bracing itself to meet the challenge of cuts in the supplementary benefit system. Our task ahead must be to ensure no-one suffers financial hardship as a result of disability.



Appealing ways

THE 100th issue of Link seems an appropriate moment to cast our minds back over the many years of the magazine's life, and remember those who have done so much to help us in the past, who continue to support our work now and hopefully will do so in the future.

TOP LEFT: First and foremost must be our Royal Patron, and other members of the Royal Family. Meeting them has always been a great privilege for those fortunate enough to be chosen, and the young gentleman pictured with Princess Anne, at the premiere of the Roman Polanski film of Macbeth, seems to take naturally to such encounters.

LEFT: Other friends of long standing are pigeon fanciers, and it was therefore appropriate that the President of the British Racing Pigeon Association, Mr L. Butler, was presented to the Duchess of Gloucester at a recent reception at the Forum Hotel, London.

CENTRE: ASBAH has been fortunate in attracting support from the Houses of Parliament. After a sponsored swim the Prime Minister, Mrs Margaret Thatcher presented the Wilkinson Sword trophy to the then Sir John, now Lord Eden, who had raised the greatest amount of sponsorship.

LEFT: Show business has been and continues to be active in the support of ASBAH's work. Mr Roger Daltry of The Who visited Five Oaks, to open the Activities Centre, to which the band contributed most generously.

FAR LEFT: Ms Joan Collins allowed herself to be portrayed in jigsaw form for the men, who work on the oil rigs, and attended the London reception to meet the prize winners.





LEFT: Mr Willy Rushton, another long standing friend is seen here in the company of Mr Cyril Levy, on the occasion of the Monopoly Marathon 1983. Mr Levy also continues to support us through his involvement in the Beaujolais Rally.



CENTRE: Mr Robert McKenzie and Lady Jean have always played a most important part in the organisation of Royal occasions, and are seen here being presented to Princess Michael of Kent, as another long standing friend of ASBAH, the Marchioness of Londonderry looks on.



FAR LEFT: Another agency which has done a great deal to help over the years is the GPO, and Mr Mike Quilty is depicted presenting a cheque for £2,000 to Miss Judy Kay, and Miss Anne Gosling, following a football match and sponsored run, shortly before Mr Quilty himself undertook a parachute jump on ASBAH's behalf.

Obviously it is impossible to mention by name all those who have done so much to help ASBAH over the years, but I hope that those who are not shown will forgive us, and continue their support of the Association's work, which allows us to sustain and increase our efforts on behalf of those with spina bifida and hydrocephalus.

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