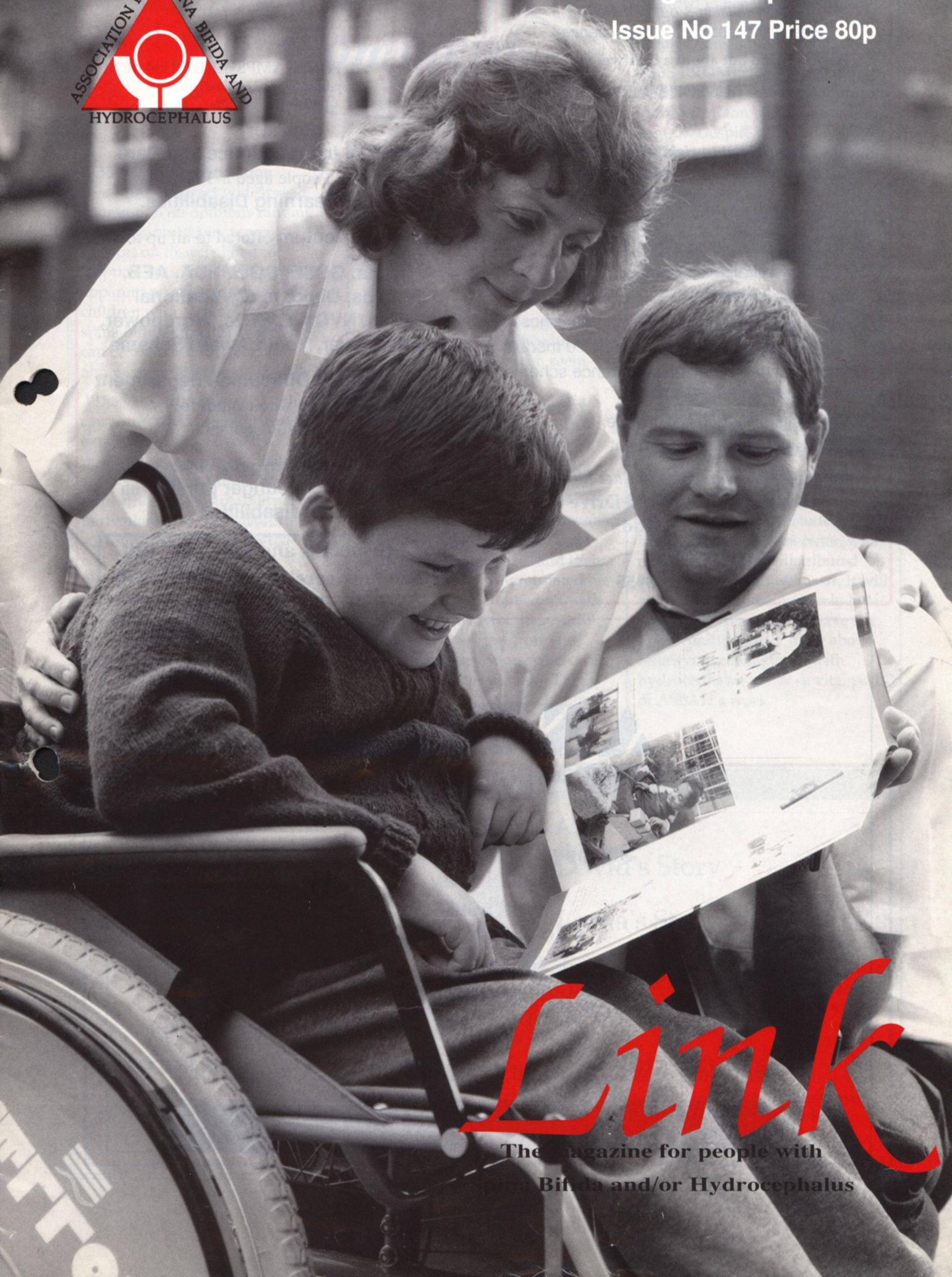


August/Sept 1993
Issue No 147 Price 80p



Link

The magazine for people with
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Comment

CONDUCTIVE education continues to attract widespread attention, with opinions ranging the full gamut from fervent support on the one hand to sceptical criticism on the other. Its apparent promise to parents of children with cerebral palsy and spina bifida - that the wheelchair can be banished for good - is almost overwhelmingly irresistible.

When such a chance is offered, it can seem perverse and churlish of experts to quibble over the presence or absence of scientific support for the method, its long-term efficacy, its suitability for a particular child. The idealism surrounding the Peto approach can contrast sharply with many parents' experience of traditional British methods, under-resourced and patchy as they are. Surely, it is felt, such dedication must bring the hoped-for result? While such an emotional response is wholly understandable, caution is needed.

In *The Price of a Miracle* (page 10) Claire Tomalin - herself the mother of an adult son with spina bifida - examines the claims made for conductive education and follows the Birmingham Project, the results of which were recently announced.

WHATEVER the challenges of Peto, those posed by the education system here in Britain can seem daunting enough. The determination needed to obtain the right statement and secure a place at the most suitable school - the sheer dogged persistence required - should not be underestimated. That such an approach does eventually succeed is shown by the stories of David and Lorna (pages 16-19) and their parents are to be congratulated on their refusal to be fobbed off with what they considered to be an inadequate response from the authorities. Their message is clear and simple: *keep pushing!* The 1993 Education Act, which comes

into force in April 1994, is intended to benefit individual children with special educational needs. Let us hope it is effective.

LESS PROMISING forthcoming legislation was recently announced in the Commons (*No, minister!* page 5). Despite typical government attempts to package the proposals as "a much more flexible system of provision", the implications for the employment prospects of disabled people are worrying. We are told that a research study shows that employers are willing to make some contribution to extra costs of employing disabled people where such costs arise. Unfortunately, as the research was not published before the government announcement, there is no way of assessing its validity. We await its publication with interest and some scepticism.

AND FINALLY... This issue of *LINK* is the first to include *Hydrocephalus Network News*, which until now has been distributed separately four times a year. It will continue to appear quarterly but now *LINK* readers will have the opportunity to read more about issues concerning those with hydrocephalus alone - a vital part of ASBAH's work.

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Cover: David Jenkinson and his parents looking through the prospectus for his new school: see 'David's Story' page 16.

Honours



CONGRATULATIONS from all in ASBAH to two of our vice-presidents - both popular TV personalities - who were awarded honours in the Queen's Birthday list.

After a career on the stage and in television, **Thora Hird** OBE has become Dame Thora. Lately she has been best known for her cameo role in the Yorkshire village comedy series 'Last of the Summer Wine' and for presenting hymn request programmes on Sunday evenings.

Michael Aspel became an OBE. Michael succeeded the late Eamon Andrews as host of the big red book show 'This is Your Life' and interviews the rich and the famous on TV chatshows.



Holiday Guides

HOLIDAY CARE SERVICE has launched their *1993 Accessible Accommodation Regional Guides* and introduced a unique accommodation reservations service.

This year the 14 colourful guides, covering the whole of the UK, have been produced in large print to assist those with partial sight and visual impairment. In addition to the accommodation listed, the guides also contain details of accessible attractions and - new this year - shopmobility schemes and area access guides.



The new reservations service, detailing hotels and self catering accommodation bookable via the guides, offers both discounted rates and the reassurance that the accommodation will be accessible. All have been inspected. There are already over 200 hotels in the scheme and the list is growing daily. The reservation line number is **0891 515494**.

Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW

Your place in karting history?

The first Renault Disabled Karting Championships is being held this year - with the organisers offering places on the starting grid to ASBAH members.

The first heat will be held at Track One in Uxbridge, West London, on 2 September but, if you miss that, do not despair! There will be rounds in Birmingham, Manchester and Cardiff later in the year.

The final will be held on 17 December, at Uxbridge with a £500 first prize and challenge trophy hanging on the result. Other placed karters will also receive cash prizes. World-class drivers from the winning Renault-Williams Formula One grand prix racing team - Alain Prost and Damien Hill - have been invited to appear.

"The contest will be competitive but no experience is necessary", said organiser John Hardcastle, of Milton Keynes-based motor vehicle adaptation company Design and Innovation, tel 0908-226688. Local Renault dealers, the British Motorsports Association for the Disabled and Motability have pooled resources to stage the championships.

Higher Educational Horizons

A conference on Improving Access for Disabled Students in Higher Education will be held in London on 11 November.

It is aimed at staff working in higher education, as well as students with disabilities and organisations concerned with education, training and employment of disabled people.

Margaret Mullany, Rehabilitation Resource Centre, City University, Northampton Square, London EC1V 0HB. Tel: 071 477 8378

Peak performance

A climb of over 19,000ft to the snowy peak of Mt Kilimanjaro in Kenya, carried out by a donor who wishes to



remain anonymous and his wife, has resulted in over £17,000 reaching ASBAH. The proceeds came from a large number of sponsors.

It has been decided that the proceeds from this magnificent effort, with matching support from the affiliated local Association, will be spent on appointing a new fieldworker for Leicestershire and Northants.

No, minister!



A recent government announcement, on the future of special schemes for disabled people in employment, could jeopardise many jobs.

A new programme for people with disabilities is to be introduced by the Employment Service from April 1994. Somewhat speculatively named "Access to Work", this will replace the help currently available under the Special Aids to Employment, Adaptations to Premises and Equipment, Fares to Work and Personal Reader Service Schemes.

Buried in the written reply by Employment Secretary David Hunt to a Parliamentary question on 22 June - a day when all attention was focused on donations to political parties - was the following:

Employers will be asked to make a 50% contribution towards assistance for employees who have worked for

them for six months or more.....

ASBAH joined other organisations representing disabled people in writing to Mr Hunt to condemn the 'deeply damaging' proposals and to call for an urgent meeting with the Secretary of State. The letter, which was also signed by the RNIB, the Spastics Society, MENCAP, RADAR, the Disability Alliance, the Spinal Injuries Association, Muscular Dystrophy and Action for Blind People, stated:

We are in no doubt that the imposition of a 50% contribution on employers will prejudice the employment prospects of disabled people.

We feel there are many employers who have struggled to survive the recession who will feel that they simply cannot afford the extra costs which will now fall on them in taking on a person with a disability. In effect this imposition will clearly be discriminatory.

In Mr Hunt's reply, received just before LINK went to press, he states that while he 'understands the concern':

I believe that the arguments for some employer contribution in respect of established employees are strong. By retaining an employee, the employer saves recruitment and training costs.

The government have not yet decided on the maximum sum to which individuals will have access, nor the maximum employer contribution to be assumed; nor what rules will apply to existing beneficiaries.

We also recognise that where a new employee is taken on and needs continuing support extending beyond 6 months he or she is in a different position from some one whose need for help first arises as an established employee. We are still considering for how long 100% support should be provided in this case.

Perhaps the summer recess will allow the government time to work out the details of these proposals and to publish the research which, Mr Hunt claims, supports his expectation that employers will be willing to make the 50% contribution. LINK will keep readers informed of developments.

Jeanette Dixon

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Caring staff raise £2,000

Staff at Marks and Spencer in Truro have presented three young people from Cornwall who have spina bifida with equipment to the value of £2,000.

The money raised by the store's Charity Committee has enabled seven-year-old Kayleigh Gibaud from St Austell to receive a lightweight sports wheelchair. The made-to-measure chair, which cost over £1,325, has allowed Kayleigh to increase her mobility skills and propel herself. No longer having to rely on parents, teachers and school friends, she can now join in sporting activities at school and at her local sports centre.

Luke Thomas from Bodmin has also benefited from the funds raised. He is now the proud owner of a Ninja Storm Cat battery-powered trike which he can operate from hand controls, making him much more independent.



Luke Thomas and Kayleigh Gibaud are pleased with the new vehicles provided by caring staff at the Truro branch of Marks and Spencer. Pictured with them are Nicola Robson, sales assistant, Andrew Spain, sales supervisor, and ASBAH fieldworker Lynne Young.

DERBY CONFERENCE

CONTINENCE AND RELATED ISSUES

A one day multi-disciplinary conference

Saturday, 9 October 9am - 4.30pm

Derby ASBAH has organised several conferences during the course of the past three years on a variety of subjects associated with the health, educational and social problems of spina bifida and/or hydrocephalus and other disability issues.

The aim of this conference is to increase mutual understanding, share knowledge and raise the level of awareness of the multi-disciplinary problems experienced by professionals and parents in the provision of care for children and young adults in hospital, school/college, in the community and support for the family.

The venue is the Post Graduate Centre at Derby City Hospital and those taking part are *Padraig Malone FRCS* (Consultant Paediatric Surgeon Southampton General Hospital); *David Thomas FRCS* (Consultant Urologist Lodge Moor Hospital Sheffield); *Ann Llewellyn* (Lecturer in Sociology & Psychology, Gwynedd); *Mary White* (Continence Adviser ASBAH); *Christine Padley* (Urology Nurse City Hospital Nottingham); *John Naudé* (Disabled Living Adviser, National ASBAH Peterborough); and *Michael Flynn* (Conference Co-ordinator, Derby ASBAH).

Application forms, which should be returned with the remittance of £12 by 27 September are available from: Mrs Anthea Hewitt, 20 Burley Hill, Allestree, DERBY DE22 2ET.

Improved Compensation for Delayed Benefits

Improved arrangements for paying of compensation for delays in payment of benefits were announced on 4 May 1993.

Prior to this, compensation was only considered when delay in payment of benefit in new claims was at least 12 months. This period is now being reduced and compensation will be considered when a claim is delayed for 6 months beyond the target set for clearing the bulk of the claim (usually between 85% and 95%).

This improvement took effect from 1 April 1993. It is recognised that this is too late for those people who claimed Disability Living Allowance last year: the Secretary of State further announced that in view of the exceptional problems following the introduction of DLA there will be a special compensatory payment to people who:

*Made a new claim to DLA, Attendance Allowance or Mobility Allowance on or after 3 February 1992;

*Were paid benefit before 1 April 1993; and

*Suffered a delay in payment of benefit of more than 8 months.

The payment will be at the rate of £10 per month for each month in excess of the 8-month period. **The customer does not need to make a claim for compensation:** the Benefits Agency has made arrangements to identify and pay those people who are eligible as soon as possible.

There will be a **telephone advice line** up and running from 21 June: 0345 227722 (calls charged at local BT rate).



PERSONAL RELATIONSHIPS



Children with disabilities are sometimes excluded from sex education lessons in mainstream school because teachers cannot imagine them having sex lives.

And when Margaret and Alan Twyford married, the paediatrician's advice on sex was a coy: "Go and find out, then come back and tell me."

The Surrey couple made these comments during the press launch of ASBAH's new video on sex and continence in June (*LINK*, June/July 1993, page 25).

Mr Twyford added: "Many people find this difficult to talk about, or may find inadequate ways to cope with the incontinence. They are then made to feel embarrassed and demoralised."

The Twyfords are among five ASBAH members in the video who discuss frankly their own experiences. The video is part of a training package produced by a team involving ASBAH research fellow Maddie Blackburn and a

team on the Design and Media Management course at Thames Valley University, Ealing.

The 18-minute video - with audiotape, illustrated handbook and product samples - is designed to give basic guidance on continence techniques and to help spark discussion.

Ms Blackburn said she felt compelled to use direct language and pictures after being told by one potential contributor: "If this results in yet another report, full of jargon and left to gather dust on an inaccessible shelf, I'm not interested."

Consumer and professional evaluation both agreed the final package should focus on continence, and be issued as quickly as possible.

■ *You, Your Partner and Continence*, £25 to disabled individuals (£45 to organisations, £55 overseas), from ASBAH House, 42 Park Road, Peterborough PE1 2UQ

Review

Towards Intimacy

National Film Board of Canada

This is an excellent video showing the experiences of a number of Canadian women, each of whom has a different disability, including one with spina bifida. The women and, in some cases, their partners talk frankly and openly about their experiences and feelings and cover such areas as self-image, sexuality and self-esteem. Both heterosexual and lesbian relationships are discussed and those taking part share how they feel their disability affected the way their sexuality was responded to.

The film runs for 61 minutes and would be very good for training days or for general viewing. *Towards Intimacy*, by allowing viewers to hear other disabled people discussing their self-image, sexuality and self-esteem, should encourage debate. By no means only for women, this video is highly recommended.

John Naudé

Concord Films Council Ltd., 201
Felixstowe Road Ipswich IP3 9BJ; Tel:
0473 715754

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, W and E Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (081) 449 0475
Regional Co-ordinator: Gina Broughton.

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (0265) 51522
Regional Co-ordinator: Meta Harvey.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (0733) 555988

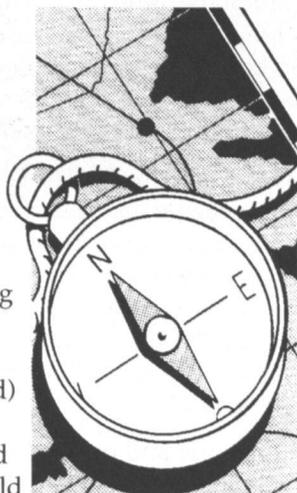
Noticeboard

The 1993 Ridgeway Wheelchair Challenge

Following the great success of last year's event, the Disabled Drivers' Association is planning another organised Trek along the beautiful Ridgeway, on Saturday 18 September and Sunday 19 September. This national trail crosses the North Wessex Downs, an area of outstanding natural beauty, linking Wiltshire, Oxfordshire and Berkshire.

The **challenge** is for wheelchair users, including electric wheelchairs, scooters and manually propelled chairs of all kinds, accompanied by supporting teams of walkers (pushing if desired) to complete varying distances along the route. The trackway is 40 miles long, sometimes rutted and stony in texture. A minimum distance would be four miles, with intermediate distances of 6,10,15 or 20 miles. The maximum distance of 40 miles could be covered in the two days. The **purpose** is to have an enjoyable outing in very beautiful and quiet countryside and, if participants wish, to raise money by obtaining personal sponsorship.

If you would like an entry form, we have a few in the Bulletin office or for further details contact: Dr. Mike Bruton, The Disabled Drivers Association, 14 Belmont Park Road, Maidenhead, Berks SL6 6HT. Tel: 0628 26767



Orange badge parking

If you are travelling to a new town and you would like to know where the Orange Badge parking bays are, contact the Disability Network. Their prepared maps show the location of reserved parking in more than 200 local authorities across the country, from Allerdale to Wyre Forest, and cost only 25p each (18p for members of Disability Network).

Disability Network Information Services, First floor, 54/56 Ormskirk Street, St. Helen's Merseyside WA10 2TF.

* A leaflet detailing how the Orange Badge scheme can be used in Kensington and Chelsea and listing disabled parking bays is available free from: Directorate of Highways, Royal Borough of Kensington and Chelsea, Town Hall, Hornton Street, LONDON W8 7X.

VAT concession

The VAT (Motor Vehicles for the Handicapped) Order 1992 came into effect at the end of December last year. The Order has given statutory effect to the previous concession to firms which lease vehicles to disabled people. Firms may now dispose of these vehicles on a tax-free basis in the open market after they have been leased to disabled people.

Ride Safely

The Department of Health has issued a bulletin alerting everyone concerned with the transport of wheelchair passengers in vehicles to the dangers of not using the proper restraints. In one case a wheelchair had been clamped in an ambulance but the occupant had no restraint other than a wheelchair lap strap. When the ambulance had to brake suddenly, the buckle on the lap strap broke and the occupant was thrown out of the 'chair.

Even under light braking and low speed cornering, unrestrained wheelchair occupants have been known to fall out of chairs. How much greater the hazard in an emergency situation or collision when forces at least equivalent to 10 times the weight of the chair and the occupant may be exerted on the restraints!

It is obviously essential that restraints capable of withstanding such forces are provided for **both** wheelchair **and** occupant and that these are **used at all times**.

Holiday Homes

In recent months the Information Department has received several



enquiries about holiday caravans and chalets to rent. There was also an urgent request to contact someone believed to be staying in a chalet owned by a local association. Unfortunately, full details of all local associations' holiday accommodation are not held at national office and we are often unable to put enquiries in touch. Could you let us have details, including contact name, telephone number and prices, of any holiday lettings run by your Association?

Please send the information to Gill Winfield, Information Department, at National Office. Thank you!

Folic acid products

A new click-pack containing folic acid tablets at the right strength for most women acting on Government advice on how to help prevent spina bifida in pregnancy is providing a financial spin-off for ASBAH.

Every pack of Cantassium folic acid tablets sold from the beginning of July will result in a 10p donation being made to the association.

The 400mcg tablet dispensers are available through 11,000 chemists and health food shops nationwide through the leading wholesalers.

"If shoppers cannot see them immediately on the shelves, remember there is a benefit to ASBAH in asking for them", said ASBAH liaison manager Paul Wootton, who negotiated the cash-for-sales donation with the manufacturer.

The manufacturer has responded positively to our suggestion that he donate some of the profit from the folic acid research breakthrough to assist with our work for people who already have spina bifida.

Advertising and packaging for the product - one of many vitamin and mineral diet supplements made and marketed by the Larkhall Group, of Putney, South London - states that 10p from each sale is going to ASBAH.

The click-packs work on a similar principle to dispensers for many artificial sweeteners. The idea is that most women - those have not had a previously affected pregnancy and do not have spina bifida themselves - can easily select their one-a-day recommended 400mcg tablet to top up their intake of folic acid.

Spectator Sports - RADAR Guide

RADAR has produced a new guide for disabled spectators visiting major sports venues in England, Scotland and Wales.

Listed under the different sports, information given includes parking, admission fees, viewing areas, commentary facilities, toilets and catering.

Editor John Stanford comments that there have been many changes since the last edition of the guide was produced eight years ago; some have resulted from legislation, such as the Safety at Sports Grounds Act, and others from a general desire to improve facilities for all spectators.

The guide is available, price £3.50 (including p&p), from:

RADAR, 25 Mortimer Street, London WIN 8AB

Events

Disabled people have rights

This conference organised by RADAR will be held at the NCVO Conference Centre in London on Tuesday September 21 and will examine the provision of services under Section 2 of the Chronically Sick and Disabled Persons Act 1970 in the light of the new community care legislation. Fees will be from £60 to £85 on a sliding scale and a limited number of subsidised places for disabled people on low incomes will be available.

Rachel Scott, Conference Officer, RADAR, 25 Mortimer Street, LONDON WIN 8AB. Tel: 071 637 5400.

A night at the opera

The Royal Opera House are providing extra wheelchair spaces at the following performances in the September - November period: 22 September *L'Italiana in Algeri*; 23 September *Madama Butterfly*; 20 October *Mitridate, re di Ponto*; 21 October *Eugene Onegin*; 4 November *Die Meistersinger von Nurnburg*; 5 November *Romeo and Juliet*. Tickets are £17.50 for opera and £14 for ballet; one companion seat is available at the same price. Access Officer Amanda Derry will be pleased to answer any queries.

Telephone: 071 240 1200 ext.123

Independent Living Conference

A Conference about disabled people's right to choice, control and freedom in their lives is to be held on 3 September at the Centre for Independent Living in Greenwich. Organised for disabled people by disabled people, the speaker will be Professor Mike Oliver.

Priscilla Tucker; Tel: 081 305 2221 (Tues, Wed and Thurs).

The price of a Miracle

The Petö method of treating handicapped children was hailed as a breakthrough, and the Government has poured money into it. But where was the proof? asks CLAIRE TOMALIN

AT THE end of the first act of Peter Nichols' play *A Day in the Death of Joe Egg*, the silent child you have seen hunched in her wheelchair comes skipping to the front of the stage and talks, like any normal little girl. It's a moment of almost unbearable emotion, because it expresses the dream of every parent of a handicapped child; that glimpse of the child who might have been.

There are about 100,000 children with cerebral palsy in this country. They are variously afflicted: their symptoms vary from mild weakness through hemiplegia (paralysis of one side of the body), difficulties with speech, damaged hearing and eyesight, to extreme physical helplessness: not able to sit, let alone stand, not able to hold anything in the hand. Some have perfectly good brains working inside affected bodies; some are mentally impaired.

Parents of all these children live with that sense of the child that might have been - the dancer, the footballer - and strain to restore their damaged child as close to the perfect image as they can. They are helped by paediatricians, nurses, physiotherapists, speech therapists, school teachers and other professionals. Some parents have bad experiences. Parts of this country are poorly served. In any case, looking after a severely handicapped child is exhausting and isolating. Parents often feel they have descended into a nightmare world in which they trail from clinic to clinic, sitting for hours in depressing hospital waiting rooms, unable to get the information they want, not always

spoken to as kindly or considerately as they should be, obliged to put their children into schools they consider second-rate, and to watch them bored, frustrated, going nowhere.

There are some first-rate medical centres and schools in Britain. There are some parents who are happy with what's on offer in their district. But orthodox medicine is not good at blowing its own trumpet, and the service is poorly co-ordinated and patchy. The parent of a handicapped child is very likely to be angry, and to need to put the blame for what has happened somewhere; where facilities are poor and under-funded, there is an obvious target for this anger and blame.

Parents of handicapped children are also especially vulnerable to offers of miracle cures. The promise that your child will rise up and skip like Joe Egg, like the neighbour's child, like your dream child, if only you will do such-and-such, or go to Lourdes, or the moon, is almost irresistible.

In the mid-1980s, parents of children with cerebral palsy heard from a man who promised them a unique and revolutionary system to help their children. He was Andrew Sutton, a specialist in East European Studies at Birmingham University. In 1986 he was co-editor of a book called *Conductive Education: A System for Overcoming Motor Disorder*, which talked of a method for treating cerebral palsy (and spina bifida) used at the Petö Institute in Budapest.

The method, devised after the Second World War by a

Hungarian physician, András Petö, involves treating children in groups, using special equipment - wooden plinths on which they sleep and exercise, and ladderback chairs which are used as supports. Its central feature is group work of great intensity, in which the children encourage one another and are guided by a 'conductor', who combines the roles of teacher, physiotherapist, speech therapist and nurse. Mr Sutton claimed that it achieved a phenomenally high success rate in getting children with walking problems on to their feet. At the end of the book he called for the setting up of a similar institute in Britain.

At about the same time, in April 1986, a BBC film *Standing Up for Joe* was put out and had an overwhelming effect on parents of CP children. It contrasted the discouraging advice given to the parents of one afflicted child in this country, and the poor quality of care offered to him, with the hopeful promises and dedicated care given by Petö. It called for parents to get off their backsides and go to Budapest.

It's hardly too strong to say the response was something like mass hysteria. The BBC received 11,000 letters. Hundreds of families set off for Budapest, raising money as best they could, splitting up husbands, wives and other children, knowing not a word of Hungarian. The press was full of stories of miracle cures: in Hungary, it was said, CP children learnt not only to walk but to skate! The terrible dread of the wheelchair could be banished for good.

Parents and sympathisers, led by Andrew Sutton, formed a pressure group, Rapid Action for Conductive Education. The media coverage and the skilfully and energetically-run pressure group produced results. There was a steady stream of press stories and television debates. The Government, never generous in spending either on research or treatment of handicap, was pushed into action. It gave money - initially £250,000, but then much more - to help set up the Birmingham Project. This was, in effect, Sutton's programme of a study to compare British methods with Petö methods, and to found an institute in Birmingham which would put Petö methods into practice. Ten British children were selected by the Petö people and sent to Budapest, along with 10 young British women to be trained as 'conductors'. After an initial period in Budapest, the children were to return to Britain and continue at the Birmingham institute, staffed by Hungarian and English conductors. Their progress was to be monitored and compared with the progress of another group of children going through the British system.

IN 1988 I was invited by the BBC to follow the Birmingham Project for a television programme. One of my qualifications was that I was familiar with handicap, having an adult son with spina bifida. I got to know some of the families involved, and I talked to many doctors and therapists.

Enthusiasm for Petö and its methods was not shared by everyone in Britain. Many British children with CP did, after all, learn to walk too. In fact, a study made in the 1960s (by Beals and Sutherland) had shown that the motor performance of all spastic diplegic children changed up to the age of seven, and that improvements were not necessarily related to treatment at all.

So there was some scepticism from the medical profession about the claims made for Petö. The sceptics pointed to the lack of verified information, or indeed any scientific account at all of its methods or success rates: when András Petö died in 1967 he left only "a handful of articles and... a small book of lectures, now virtually unobtainable, edited under his supervision" (Andrew Sutton). Petö was also known to select its children, excluding those with severe mental handicap, and reject 10 per cent of its intake after the first two years.

I myself was told by the principal, Dr Maria Hari, when I visited the Petö in May 1988, that although official statistics claimed that between two-thirds and three-quarters of the children left the Institute "orthofunctional" - able to lead normal lives - the proportion that went on to lead normal working lives as adults was very much smaller. In Hungary, doctors said children often "failed" after leaving the Institute.

Further scepticism was based on the difficulty of establishing a proper control group. When I talked to a neurologist, Professor Patrick Wall of St Thomas's Hospital, he confirmed that, while there was obviously a need for a properly controlled study, it would be very difficult indeed to set one up. Children with cerebral palsy may present apparent similarities, but the damage to their brains was likely to be completely different. Purely descriptive accounts of their weak and strong points at any stage did not mean they were necessarily comparable.

The scepticism of some British paediatricians, physiotherapists and educationalists was reinforced by their belief that there was already some very good and successful work being done in this country, and that to divert large sums of money to one project with a questionable scientific basis was not the best thing to do.

Below: The author Claire Tomalin, pictured with her son Tom and his 'streetwise' wheelchair.





Above: Conductors at the Petö Institute work very closely with the children.

There was another fear expressed: that to encourage vulnerable parents to believe their children might be miraculously cured was unkind. Against this, I have noticed that parents show a remarkable capacity to adjust their expectations over the years and mercifully forget their earlier hopes. Those who take their children to Lourdes expecting a miracle, for instance, often come back convinced that there has been one, although no one else can see any change. What has changed is their attitude.

My impression of the parents whose children were involved in the Birmingham Project - a brave, admirable group they were - was that they did like and trust the Petö Institute. They also frankly said that they enjoyed being involved in an adventure. Instead of simply being stigmatised as unfortunate, they became almost heroic figures.

Other parents have had varied responses to Petö, but just about everyone who went there found it a very attractive place. It offered a source of inspiration, a comfort, a faith to people who were suffering: seeing some children who had

learned to walk, they believed their own children would do the same. It also offered a unified system. The sheer hard work, the order, the idealism and self-sacrifice displayed by the conductors - as well as the orderly and highly motivated activities of the children - all this presented a striking contrast with the long waits at clinics, the short day of the British special school, and the sense of muddle, uncertainty and sadness that often hangs about it.

It struck me that there was even an implied criticism of our whole society underlying some of the praise for the Petö methods,

Hydrocephalus Network **NEWS**

ASBAH, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.
Telephone: 0733 555988 • Registered Charity Number 249338



SUMMER '93

Smiling Through

Only 48 hours after an additional shunting operation into the fourth ventricle, four-year-old Kylie Pratten (right) was smiling brightly for the camera. Kylie, from Cleethorpes, underwent the operation at Sheffield Children's Hospital in May, having had her first shunt fitted when she was about a week old. When her relatives arrived from



Torquay to visit her in hospital they were amazed to find her in such good spirits. She was allowed home the following day to convalesce and is now making good progress with the help and support of her family.

"I hope this happy photograph will be an inspiration to other families in a similar situation", writes Kylie's aunt.

New fieldworker appointed

Following negotiations with the Leicestershire Association, we are pleased to announce that a new Fieldworker, Mrs Pat Waller, has been appointed for Leicestershire/Northamptonshire.

A substantial upfront donation from a sponsored activity (see *LINK* page 4) to support our 'Fund a Fieldworker' campaign in the area has been matched by an annual commitment from



Leicestershire ASBAH. This cooperation and good relationship between National office and the local association has led to a secure three-year funding for the position showing, once again, the benefits of good coordination of efforts between the National and the local elements of ASBAH.

Pat, a former teacher, will join ASBAH on 1 September

Opinion

by
Jayne E. Allerston

□ I THINK that there is a great deal of ignorance about hydrocephalus and its effects. Even teachers do not understand and I do not think I am the only person whose confidence has been affected because of this. When I asked for help and could not explain the problem the teachers would label me lazy or say I could not be bothered. We can be treated too "normally" and too much may be expected of us so that we don't get enough individual help. My main problem was science - this lesson I really dreaded. I felt I could not talk to my science teacher and I was frightened of what might happen if I did own up to my problems.

The general attitude when it came to leaving school was you're going away and getting independent whether you like it or not. Okay, the ones that get there and cope do appear to be happy and content but this isn't right for everybody. I wonder whether people living alone because they have been pushed into independence felt that they can't ask for any help they may need later. I have felt similar feelings when pushed to do certain things myself. When people used to expect me to do things that I found too difficult, it really got me down.

As a result of all these pressures I have experienced a very bad depressive illness and have not done anything much since, only bits of voluntary work which my doctor prefers to call occupational therapy. I am now well and the problems I have written to you about have in my case improved vastly or I would not be writing this letter so confidently now, but this is beside the point. There are young people now with spina bifida and hydrocephalus at school or away at college who may be going through the same pressures as I did when I was in that sort of situation and unable to tell someone.

I think we should all have a fair chance to decide what we do with our lives and have help if necessary in making our own decisions, definitely when the individual becomes 18. The choice should be open to us to stay at home with our families if that is what we want. Living independently or living in a home are not the only choices. We should be given help to achieve more and be as happy as possible in life wherever we are.

Thank you, *HN News* readers, for reading what I consider is a very important letter in favour of the quality of life I believe everyone deserves, no matter what.

ACE Advice Service

The Advisory Centre for Education is a national independent education advice service for parents of children in state-maintained schools. ACE's staff deal with every conceivable kind of question on education - from access to school records to welfare benefits - and in a typical week a quarter of the calls they receive will be about special education referral, assessment and allocation procedures. The service is provided free of charge.

ACE has an **advice line** on special education needs between 2pm and 5pm on weekdays on **071 354 8321**.

*Advisory Centre for Education,
18 Victoria Park Square,
LONDON E2 9PB.*

Computer help

THE AIDIS Trust specialises in providing computers for young people with disabilities aged from about 10 years upwards.



The Trust is known to and well thought of by the Princes' Trust, and they prefer requests to come direct from the young people themselves. ASBAH can help with the wording.

**Apply to: The Director,
AIDIS Trust, 1 Albany Park,
Cabot Lane, Poole, Dorset
BH17 7BX**

Hydrocephalus

- the first ten years



A beautiful summer's day more conducive to lying on the beach than to sitting in a lecture room did not prevent a good turnout for the ASBAH South East Region's Study Day *Hydrocephalus - the first 10 years*, writes **Marshall Thomas**.

Over 50 people attended, mostly parents of children with hydrocephalus. However, also present at the Highlands Hospital Academic Centre, Winchmore Hill, North London, was a 70-year-old lady who only recently found out that she had hydrocephalus.

Following a brief introduction by regional coordinator Gina Broughton, Dr Roger Bayston gave a comprehensive presentation on hydrocephalus and its treatments. Using diagrams and images, he opened by summarising the main causes.

He then went on to explain the pros and cons of the various types of shunt, starting with the introduction of the first silicone shunt in 1958, and the effectiveness of

the different types of drug used to treat infections that cause shunt blockages. Finally, he outlined the most recent research and development projects taking place in the UK and the United States.

An extended 'question and answer' session followed, during which the mechanics of shunts were further explored. Added to this, several parents also raised the point that 'expert' medical decisions have sometimes conflicted with what they themselves have learnt during their experiences of raising children. Indeed, because of such decisions, some of their children have spent prolonged periods undergoing unnecessary treatments.

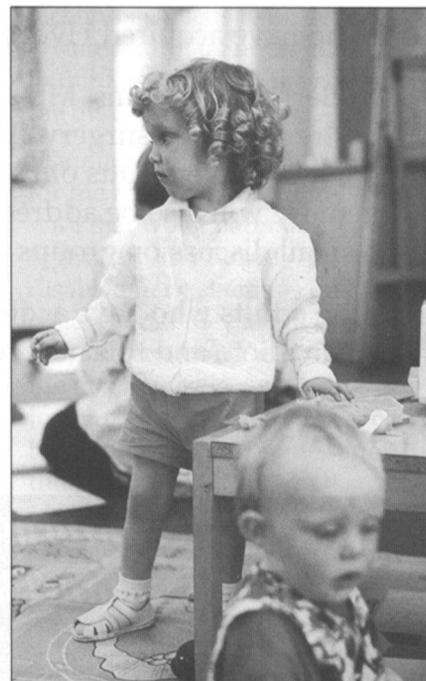
The morning session concluded with disabled living adviser Leonie Holgate giving a talk on learning difficulties with some positive suggestions on how to approach them.

Having explained the nature of some of the sensory impairments and perceptual difficulties experienced by

children with hydrocephalus, Leonie discussed ways in which one can help compensate for these. She also gave a number of tips on how to overcome the 'invisible' symptoms of hydrocephalus, such as loss of concentration and short-term memory.

To finish, Leonie highlighted the positive aspects displayed by children with hydrocephalus, including their responsiveness to colour and touch. This provided a useful basis on which to build during the afternoon discussion groups.

Four scheduled discussion groups were each run twice during the afternoon to allow everybody to go to more than one. They were: Early Play and Learning for the under-5s (Leonie Holgate); Education and Statementing (Dr Katie Simmonds, Independent Panel for Special Education Advice); Siblings/Family Relationships (fieldworker Jo Rees); Computing for the Under-10s (Audrey Podmore, Hatchford Park School, Cobham).



Monday 15th November 1993

Spina Bifida, Hydrocephalus & Education

*Venue: Westland (Yeovil) Sports & Social Club,
Westbourne Close, Yeovil, Somerset BA20 2DD*

Funded by a grant from



HTV WEST

Spina Bifida & Hydrocephalus will be explained, and their implications for education will be explored. Particular emphasis will be placed on the consequences for learning of Hydrocephalus; the educational Statementing process; continence management in schools. Acquiring mobility skills and disability awareness in the mainstream school will also be addressed.

Contributors to the programme will include Dr. I.D. Sugarman MB ChB FRCS (Ed) Southampton General Hospital; Mrs. Leonie Holgate, Mr Peter Walker, Mr John Naudé and Mrs Jane Williams - ASBAH Disabled Living Advisers.

Saturday 20th November 1993

Acquiring Hydrocephalus as an Adult

Venue: ASBAH House, Peterborough

If you have acquired Hydrocephalus during adult life, then this day will be of interest.

Mr Bernard Williams, MD Ch.M.Birm. MB ChB FRCS, Consultant Neurosurgeon, Midland Centre for Neurosurgery & Neurology, will speak on the medical aspects of this condition. Other possible results of Hydrocephalus, such as perceptual alteration and changes in memory will also be addressed. There will also be the opportunity to compare experiences in small discussion groups and to talk to ASBAH staff on specific topics.

More adults who have acquired Hydrocephalus contact ASBAH for support and information, and this new type of Study Day is a valuable opportunity for us to listen and learn from you.

***For further information about both Study Days, please contact:
Mrs Lynn Thomas, DLA Secretary, ASBAH House
Tel: 0733 555988***

training and atmosphere: we tolerated sloppiness and let our children be "lazy" (I heard a parent use this word). The Hungarians didn't. Communist methods - group work, authoritarianism, very large demands on conductors - were strangely appealing to capitalist parents.

I had reservations when I watched large groups of very small children institutionalised in rooms with high windows, following almost military-style routines, and British children crying and exhausted by the hours of physical efforts they were asked to make.

Still, my clear impression is that the parents liked the fact that their children were taken away from them and put into the hands of conductors for very much longer than they would be in Britain. This is not because the parents don't love their children, but because they are worn out by the demands made on them, the slavery - not too strong a word - involved in giving proper care without proper support. It is a point that badly needs to be addressed in this country.

I was also worried by Dr Hari's vehemently expressed loathing of the wheelchair. She said it was terrible to be tied to one, and I have noticed that parents have said again and again that it is the idea of their child in a wheelchair that they find unacceptable. All the English parents started with the belief that their children would learn to walk - it was **not walking** that seemed most terrible to them. Yet since wheelchairs are essential to many people - victims of war, accidents, strokes, as well as paralysed and handicapped children - it seems odd to single out the wheelchair as a symbol of horror. Better surely to improve its design and make it into a decent, even attractive, accessory. When I was able to buy my own son a Californian wheelchair, it changed his life because it was so good to handle; it changed my life,

because I could fold and lift it without strain; and it changed the attitudes of everyone he met, because it looked streetwise, more like a bicycle than an invalid vehicle.

Pető itself, to which I have not returned since 1988, is said to be changing even as its methods are being borrowed here. One parent, whose daughter went there for a year, says it is no longer the place it was: "The goose that laid the golden eggs has been killed," she said, meaning that the methods have been diluted by the enormous influx of foreign children, and that the end of the Cold War has allowed the clever young conductors to leave.

This mother is still grateful for the work they did with her child. But she has now drastically lowered her expectations for her daughter's future. It doesn't look as though she will be able to walk more than a few steps without help. I asked her whether, since she is an exceptionally intelligent person, she had not looked into the scientific basis for the Pető method, and some accounts of its long-term results, **before** she took her daughter there. Did she not ask, for instance, where all the "orthofunctional" adults, who should be stepping forward to testify to the efficacy of the system, are? But she answered that she had never thought to put such questions. She went as a mother, she said, not as a scientist.

THE results of the Birmingham Project, just announced, indicate that the Pető method works no better than British methods: when compared with children with matched special needs in the control group in Manchester, there was no evidence that the Birmingham children would achieve better rates of progress. Pető adherents are claiming that the research itself did not have a proper scientific basis, which may well prove to be so. But if it is, it is extraordinary to find that the Government is already committed

to putting £5million into a new international training centre at Pető to train more British conductors and accommodate more British children.

This training rests on a system which has never been explained in scientific or medical terms, even by its founder. Meanwhile, research into treatment of handicap that is **not** tied to conductive education still suffers from lack of funding in Britain. It may be that any research, any funding, is better than none. All the same, what we have seen is a skilfully managed pressure group, encouraged by a highly emotional and dubiously scientific television film, pushing the Government into making expensive gestures to placate the pressure group before they have scrutinised the results of the research they funded. Now the results are here, it looks very like a major blunder.

Wouldn't it be better to spend money steadily to improve services in Britain? For example: research into prevention and treatment of handicap demands a chair at a university. There should be a structure for pooling information and coordinating work done in the different regional centres and schools. Much more should be done to support parents with advice, information, nursery schools, respite care. Wheelchair technology needs to be developed, architects and planners educated to think routinely of the needs of the disabled.

Planning for long-term provision for the handicapped would help with that worst parental nightmare, the future. The adult disabled have claims as great as children, but they are overlooked: they are not found as charming by the media. Really standing up for Joe must mean, not a miracle cure, but sitting down to some serious thinking about priorities.

** This article first appeared in The Independent on Sunday on 16 May 1993.*

Leeds Castle

Surrounded by 500 acres of magnificent parkland and gardens and built on two small islands in the middle of a natural lake, Leeds Castle is England's oldest stately home. Originally a Saxon fortress built in AD 857, it was rebuilt in stone by the Normans and later converted to a Royal Palace by Henry VIII. Visitors with disabilities are warmly welcomed and can take advantage of special reduced admission rates, which have been held at 1992 levels. An "Information for Visitors with Disabilities" leaflet, prepared in consultation with the Holiday Care

Service, is available from: Leeds Castle, Maidstone, Kent. ME17 1PL. Tel: 0622 765400



The Historic Dockyard

Not far from Leeds Castle, at Chatham in Kent, is the



Historic Dockyard. A royal dockyard for four centuries, Chatham provided over 400 ships for the British fleet, including Trafalgar's finest wooden warships - HMS Victory, Temeraire, Revenge and Leviathan. Now a living, working museum, the site is the most complete Georgian dockyard in the world. Most buildings have wheelchair access and staff will be pleased to assist.

A free leaflet detailing access is available from: Freepost 29, The Historic Dockyard, Chatham, Kent, ME4 4TE. Tel: 0634 831125.

Riding in Kent

Leybourne Grange Riding Centre for the Disabled is situated in 80 acres of parkland near West Malling in Kent and offers horse riding instruction, therapy and recreation for physically and mentally disabled people.

The Centre, formerly part of Leybourne Grange Hospital, faced closure late last year when the hospital withdrew from the site. It has now been "rescued" and operates as an independent charity which aims to improve and expand the existing facilities.

For further information contact: Leybourne Grange Riding Centre for the Disabled, Birling Road, Leybourne, Nr. West Malling, Kent. Tel: 0732 872844

Ashwellthorpe Hall Hotel reopens

Ashwellthorpe Hall near Norwich has reopened as a hotel equipped for wheelchair users and other disabled guests, together with their relatives and friends.

The Disabled Drivers' Association, which owns the Elizabethan house, had to close the hotel facilities last autumn. However, a group of users has now formed an association to manage the accommodation.

For further information, contact: The Manager, Ashwellthorpe Hall Hotel, Ashwellthorpe, Norwich NR16 1EX.

Field Study Centre in Highlands

The newly opened Highland Field Centre in Ross-shire has been designed to be accessible to wheelchair users. Its accommodation is in log cabins adjoining the main building and there are 10 twin bedrooms on the ground floor, together with wheel-in shower rooms.

Groups of young people or adults are taken on a full board or self-catering basis, and a range of activities and studies is available.

For further information, contact: Jim Monahan, Centre Director, The Highland Field Centre, The Old Inn, Strathconon, By Muir of Ord, Ross-shire IV6 7QQ. Tel: 099 77 260

Arts and Disability Guide for Yorkshire and Humberside

Yorkshire & Humberside Arts has published a revised Regional Arts and Disability Guide.

The booklet covers a range of issues, including physical access, employment, equipment and training, sources of funding and advice, as well as giving information about those arts organisations which are involved in projects with or for disabled people.

Copies can be obtained from Yorkshire & Humberside Arts, 21 Bond Street, Dewsbury WF13 1AX. Tel: 0924 455555.

Wheelchairs afloat!

Boats for the Handicapped Association has a range of boats based on the Basingstoke Canal in Hampshire which are designed for disabled people.

These include the *Mildred Stocks*, a self-drive boat for day cruises by groups of up to 12 passengers, six of whom could be in wheelchairs. Half and full day bookings are taken.

The organisation also has a twin-hulled single or double seat rowing boat, canoes and a sailing dinghy.

For further information contact Mrs J.M. Gerry, 10 Fairland Close, Fleet, Hants GU13 9LU. Tel: 0252 622520.

Small Business Programme - Training for people with disabilities

Queen Elizabeth's Training College is organising a course for disabled people who wish to set up their own business or become self-employed but do not have sufficient business knowledge to do so.

The Small Business Programme is an 11-week course and includes marketing, finding finance, making financial forecasts and finally producing a business plan. The course will also look at the practical aspects of running a business such as communicating effectively, book-keeping and administration. There are facilities for each person to use computers running the latest software.

For further information contact: Mrs Pamela Martin, Small Business Programme Tutor, Queen Elizabeth's Training College, Leatherhead, Surrey KT22 0BN. Tel: 0372 842204



ICELAND
1994



The Icelandic government has decided to endorse an international conference where important topics regarding the quality of life for disabled people will be on the agenda. It is being organised jointly by the National Federation for the aid of the handicapped (Landssamtökin Thorskahjálpi), the Organisation of handicapped in Iceland (Oryrkjabandalag Islands) and an American organisation named United World Partnership on Developmental Disabilities. The conference will be held in co-operation with the United Nations and will take place in Reykjavik on June 1-3, 1994.

The main themes will be Beyond Normalisation, Putting awareness into action and One Society for all and will be covered by invited key speakers and by papers on related issues.

Wheelchair Information Pack

A wheelchair tailored to suit an individual user's needs should provide comfortable, functional mobility. Recent technological advances have resulted in the design and production of many more 'state of the art' wheelchairs which enable their users to maximise their wheelchair mobility.



Wheelchair Information is the first of a new series of Disabled Living Foundation specialist information packs - a fully illustrated guide through the maze of manual wheelchairs and pushchairs and electric vehicles which, when used together with other wheelchair-related equipment, help to make the user more independent. Topics covered by 11 loose-leaf sections include manual and powered wheelchairs for children and adults, accessories, seating systems, clothing, "out and about", and supply & provision. Each section is complete in itself so that readers can dip into a relevant part of the pack and do not have to cross-refer constantly from section to section.

In recent years, the number of requests for information on high performance wheelchairs and electric vehicles has increased dramatically. Enquiries about pressure relief cushions, correct seating and ways of lifting wheelchairs in and out of cars are also on the increase. With the help of the *Wheelchair Information* pack, advisers should be able to provide wheelchair users, their relatives and friends with clear answers to these and other questions.

The pack is available either separately for £35 from the DLF or as part of the course material given to delegates on one of the following new DLF courses which cost £75 per delegate per course.

**Maximising wheelchair mobility for frail elderly users
and
Pressure relief and wheelchair users.**

For further information please contact Rosemary Good or Nicola Stacey, Disabled Living Foundation, 380-384 Harrow Road, LONDON W9 2HU; Tel: 071 289 6111.

SPINA BIFIDA OCCULTA *and tethered spinal cords*

In my article in the last issue of LINK (No. 146, June/July, p.12) I stated that "In spite of having some features in common with meningocele, spina bifida occulta...has an entirely separate pattern of inheritance". This statement has been challenged and indeed there are a number of published papers indicating that there is evidence that if spina bifida occulta arises in a family then the risk of open spina bifida occurring is the same as for meningocele. It is therefore wise for affected families to take all precautions including making sure that the mother takes appropriate doses of folic acid before and immediately after becoming pregnant, and that the pregnancy is screened for the early detection of abnormal development of the brain and spinal cord.

Carys M. Bannister

As September approaches, bringing the start of another school year, parents all over the country will be facing decisions and challenges over their children's education. What is involved in obtaining a statement for their child? Can they be sure of getting the school of their choice? LINK looks at the experiences of two families and outlines the changes the 1993 Education Act will bring.

David's Story

by
Tony Britton

It took an 18-month battle, the threat of an appeal to the Secretary of State and a change of leadership in the education department for one couple to win permission for their son to go away to boarding school.

Geoff and Helen Jenkinson became increasingly worried about the support which would be offered to their son, David, when he transferred to secondary school - claiming he had already been sidelined at local primary school after hip operations.

David, now aged 10, has spina

bifida and hydrocephalus. After the operations, he spent six months in a 'hip-spiker', a plaster cast from shoulder to toe.

His parents complained to no avail that he was getting too little physio and OT to improve his mobility. They said he was not involved in competitive sports with classmates.

Indicative of the inadequate level of support from the LEA, they claimed, was that the classroom assistant had to risk her health by lifting him single-handedly in and out of the taxi at school.

The idea of sending David away from home gelled during 1992, when David was nine years old. His gradual acceptance helped quell pangs of parental conscience.

"He was very apprehensive at first, but now he's looking forward to going in September", said Mr Jenkinson.

The Jenkinsons visited Lord Mayor Treloar College in Hampshire after hearing through their local ASBAH about the the skill and care the college puts into independence training as part of the school curriculum.

"We were looking at what David would be like in 10 years time and felt that Treloar offered him the best chance for adult life", said Mr Jenkinson, a telephone engineer.

A letter was sent to their local education authority - Barnsley - in April 1992. It asked the council to pay for David to go to Treloar.

Students in the Craft, Design and Technology Class at Lord Mayor Treloar College where David will be going this September.



"Barnsley just did not want to know. At first, they insisted that they had an integration policy which would meet all his needs and then offered a place at a local special school. They wouldn't budge."

In December, the Jenkinsons received David's new draft statement of special educational needs - naming a special school in Barnsley as suitable. The couple and ASBAH education adviser Peter Walker had their doubts; they did not believe it contained enough role models for a lively lad with spina bifida. The Jenkinsons lodged an immediate objection.

The couple asked the council to have David's new statement ready for 19 March. In the meantime, they visited their MP, who confirmed there was no fast-track to the Secretary of State. If they refused to accept the school offered by Barnsley, their appeal would have to proceed its normal course through the education authority. This, they feared, might leave their son's future in limbo for months.

Then came a phone call which hit the parents like a bombshell. The senior officer involved said that, because he was taking early retirement, there could be no further decision until his successor was in post.

Instead, the phone call turned into the harbinger of the best bit of news they had received for some time.

On the Thursday before Easter - just three weeks later - the Jenkinsons received the decision they hardly dared to hope for. The new senior officer informed them that Barnsley would pay for David to go to Treloar, and that he could be enrolled this autumn.

"The story shows that, if parents want something badly enough, they've got to be prepared to fight and not accept any decision from the education authority", added Mr Jenkinson.

Lorna's story

by
Alison Twomlow

We started the process of obtaining a statement for our daughter Lorna, who has spina bifida, in July 1991 by going to the local school to meet with the headmaster and talk over her education.

He was most helpful and contacted the educational psychologist, to let her know of Lorna's problems and to arrange for her to meet us. This meeting took place a few weeks later and all seemed to be going well. The psychologist thought that as Lorna was only just three they would review the case in six months.

In hindsight this was our downfall.

We heard nothing until I contacted them again the next June, and again we had another visit and then a letter from the education authority saying that they would be issuing a section 10. By this time I had visions of visiting her in some sort of penal institute, bars and all, but after inquiring what a section 10 was we were told it was a formal request to obtain medical information, to assess her needs. We were sent a form to fill in, saying what we felt her needs were, which we duly returned in June and then heard nothing for several weeks.

Again, another pitfall in our endeavour was that Lorna was unwell and needed further surgery, so I was not able to keep

To Statement or not?

Often parents of children with hydrocephalus alone are reluctant to have their children statemented, maintaining that they appear to be progressing well in the primary school or that the ancillary provisions necessary are being provided by the Local Education Authority.

Experience has shown, however, that as children with hydrocephalus progress through the primary sector the educational gap between them and their peers becomes ever wider. By the time they enter secondary school they are finding it increasingly difficult to cope with the system of changing classrooms, changing teachers, pressure of work, peer pressure and the emotional difficulties often encountered during puberty.

In addition, although resources are at hand at the moment, in times of continuing financial hardships for schools and educational authorities, they can be withdrawn at any time. Whereas **if these resources are specified on a statement** the LEA is **legally** bound to provide them.

ASBAH strongly advises pupils with hydrocephalus to be statemented as early as possible for, as we have seen, it can often be a lengthy process.

Peter Walker

pestering the education department for several weeks, during our stay in Nottingham.

By October things were under way again - in fact, all hell was let loose. I had people telephoning to make appointments and visitors constantly at my door, as "did I realise that it was only a few weeks until Lorna was due to start school"(!) After that constant stream of assessments all went quiet in November. Then - catastrophe of catastrophes - the school decided to bring the Easter intake of pupils forward and this meant that Lorna would start school on February 17th. By December I was assured that all would be sorted out in the New Year. I forgot to ask *which* New Year!

By January I was told by the

educational psychologist that it really didn't matter if things weren't completed by the time Lorna started school. This was when I saw red. It didn't matter to *them*, but it certainly did to *me*. I had had people knocking on my door after six weeks away from home, with a child still recovering from major surgery. Our lives had been totally disrupted and I am ashamed to say that I told them this in no uncertain terms. I demanded assurance that it would be ready on time.

On February 13th, Lorna's draft statement arrived. You may think we are getting near to the end of this story - but no. Her medication had been written on the statement wrongly and I was advised not to accept this as, according to her records, she needed sedating

instead of requiring a nominal dose of antibiotic.

Having been assured that this could be easily rectified, I was informed a week later that the statement would have to be retyped. Yes, it *was* only one spelling mistake but this would delay things for another month.

This was when I both looked and sounded like Victor Meldrew: *I DON'T BELIEVE THIS!* After much ado, and demanding to speak to the Head of Department, they miraculously managed to get it all signed in an hour and it was pushed through at the meeting the following Thursday. Lorna at last had her formal statement, and the school was allocated a budget to look after her.

Lorna has now been at school for

THE 1993 EDUCATION ACT -what it means for parents

The Act will come into force as from April 1994. Listed below are some of the changes which will benefit individual children with special educational needs and their parents.

- All schools are to **publish information** on how they meet children's special educational needs as part of their Annual Report - including details of their screening and assessment processes, teaching strategies and the use they make of LEA resources. If your child has special educational needs but has not been 'statemented' you will, for the first time, have a right to know in some detail how your child's school is geared up to respond to his or her needs. This information will help you to decide whether or not you should be asking the LEA for an assessment.

- The Government is to publish a **Code of Practice** which Governors of schools and LEAs must 'have regard to' when making decisions relating to the assessment of pupils' needs and making provision to meet those needs.

- If your child doesn't have a statement and you ask for an assessment under the 1993 Act, the LEA will have to regard this as a request for a **formal assessment**. Up to now, LEAs have been able to give a child any old kind of assessment in response to a parent's request.

- If you LEA decides not to issue a statement following their assessment of your child, you will have the **right to appeal to the Tribunal** (see below for details). At present, the right of appeal is to the Secretary of State - who can only ask the LEA to 'think again'.

- Regulations may relieve an LEA of having to obtain a full set of professional reports for every assessment. So, if your child has learning difficulties but obviously no relevant medical condition, the LEA may be able to **skip the Medical Report**, saving time.

- When you are sent the draft statement, it will not name the school or the type of school the LEA thinks is appropriate. **You will then be able to tell the LEA which school you would prefer to see named on the statement.** If the LEA do not go along

four months and has settled very well. In fact she complains when it is weekends and holidays because she misses her friends!

Last week was sports day and Lorna wanted to join in. For a whole week we had explained to her that it didn't matter about winning, it was the fun of taking part. But on that afternoon I wasn't the only mum with tears in her eyes, as she won the "egg and spoon" race, to the rest of the school chanting her name! If she had won the Olympics we couldn't have felt any prouder.

We have received Lorna's first school report and her teacher says she is coping very well with all aspects of school life, and achieves in her own quiet, independent, determined way.

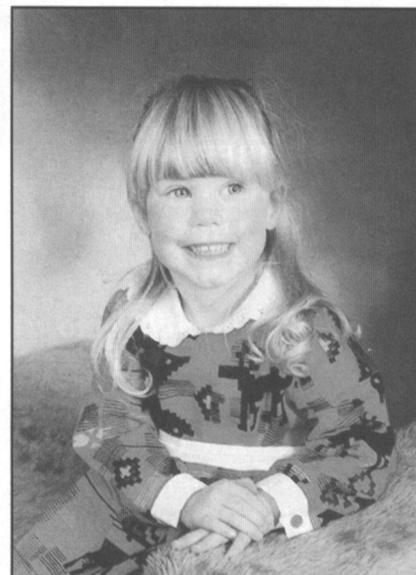
We cannot praise the staff and

school enough for all the support they have offered us, the Headmaster for all the help given during the statementing time, and Lorna's ancillary helpers, who have helped her gain so much confidence.

We have achieved our main goal. Lorna is at a school where her disabilities are accepted and she is treated as any other child.

I feel like Aesop now. The moral of this story is that, if you are going through this process, **keep pushing**. Let the switchboard operators at County Hall recognise your voice, ensure that you are not being pushed to the bottom of the typing pile. If you don't shout about it, no one else will. Your child is the most important child in the County and only the best service will do!

Lorna Twomlow, now happily attending school where she is coping very well and making many new friends.



with your preference, you will be able to appeal to the Tribunal.

- Regulations will be drawn up **limiting the time** an LEA can take assessing your child (probably six months) and setting a deadline by which a statement must be finalised, following the issue of the draft statement.
- When the statement is finalised, the LEA will have to **name the school** they consider appropriate on the statement. If there is no school named, you will be able to appeal to the Tribunal.
- Regulations will be drawn up giving LEAs a procedure which they will have to follow when **reviewing statements**. At present, they can do as much or as little as they like.
- The school named on your child's statement will have a legal **duty to accept** your child.
- You can ask for the school **on the statement to be changed** as long as it is over a year since the statement was issued or since you last asked. If the LEA refuse, you can appeal to the Tribunal.
- If you **move home** into another LEA area, the new LEA will have a duty to make the provision set out in the old LEA's statement.

- The LEA will not be able to **cease to maintain your child's statement** unless 'it is no longer necessary'. You will have the right to appeal against this decision to the Tribunal.

- **The Tribunal will replace both the local appeal committee and the Secretary of State.** Its decisions will be binding on LEAs. The Tribunal will be able to:

- a. require the disclosure of any relevant documents;
- b. require relevant witnesses to attend;
- c. place witnesses on oath;
- d. 'correct any deficiency in a statement', with the agreement of both parents and LEA.

The new legislation has still to complete its passage through Parliament, but the changes above are secure - most of them having been proposed by the Government itself. The next stage for parents to look out for is the publication of the Code of Practice. This will be circulated in draft form, for comment, in the early Autumn.

John Wright, Administrator, Independent Panel for Special Education Advice.

ASBAH Pioneers

LIFE MEMBER Frank Armour has been giving us a lesson in ASBAH history and good manners!

He has written to *Link* to suggest it was high time we recorded the invaluable service of some older members - who have repeatedly appeared in these pages from the early days until the present.

As he flipped through back numbers, he picked out four people who appeared in the first nine issues. We still see them on the back page today!

There were Mrs E Grant (North East) and Miss F Seward (North Yorkshire), who first came to light in Spring 1967. It must have been a good year because Mrs J Carter (Mid-Wales) joined Frank's list that summer. A year later, in came Mrs G D Brown of Hull.

"It would please a lot of people to see some recognition given in *Link* to these veterans. It might even encourage those who think they might be tiring after shorter innings", he wrote. Frank listed seven others who were all there in the winter of 1972.

The editor couldn't agree more. Without the selfless devotion of volunteers like these, ASBAH would not have had any organisation at the grassroots.

In this, the first of an occasional series of profiles, we spoke to Joan Carter and Gerritje Brown.



JOAN Carter joined the ASBAH family soon after the birth of her daughter Sara-Ann. Her front room and kitchen at Craven Arms, Shropshire, were first thrown open to other parents in 1965.

The local association of which she is chairman stretches from deepest Welsh Wales at Aberystwyth, where members have a caravan five minutes walk from the sea, to the border counties, where Englishness is the order of the day.

The Edwardses, the Prices, the Grosvenors, the Olivers, the Williamses and other families chuckle over their differences but muck in where it matters - getting the best for their youngsters, and involving the youngsters as they grow up.

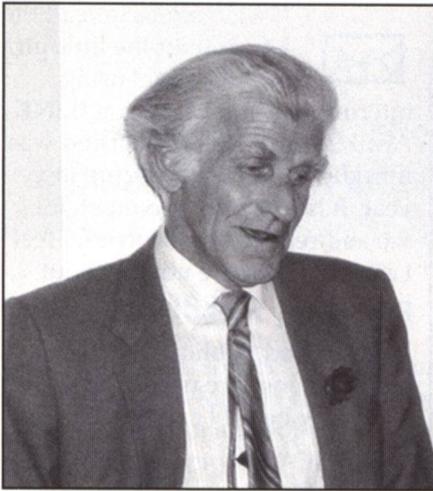
"I'm Mid-Wales ASBAH through and through. The work is as important to me now as it was when Sara was alive", said Joan. Sara died eight years ago; she would have been 30 this year. The

visitor senses they had good times together, more adult-to-adult than mother-to-child. Family photos occupy pride of place on the sideboard.

Joan, a widow for 26 years, still spends time at her typewriter and phone, working for Mid-Wales ASBAH. There are magazines to get out, members to chase, advice to be offered, a shoulder to lean on.

And, at the age of 71, she thinks nothing of rushing round the village in her little red car - although when *Link* called she was having to face up to the prospect that she might have to give up the car because it was becoming just too expensive to run.

Joan was born in Hereford and brought up in Birmingham before marriage brought her back to the Borders. At heart, she's a no-nonsense Brummie just busting to get out: 'when something's got to be done, you just do it,' she says. ■



ONE ASBAH pioneer should not be forgotten. His name actually appeared on the back page of *Link* No 1 - way back in spring 1966. And it was none other than **Frank Armour**, himself, the instigator of this series.

Modest Frank failed to remind us in his letter that he was ASBAH's first hon general secretary before we had any offices and that he was finance officer until 1984, followed by a spell as telesales accountant until retiring two years later.

Since then, he has kept busy at his home at Horsham, Sussex. There's lots of cricket to watch, three mornings a week with his local CAB and a new wife - Mary, born in Wiltshire, whom he brought back from Australia after marrying her in 1990. ■

THE clue is in her first name. So it was not totally surprising to learn that, when **Gerritje Brown** and members of Hull and District ASBAH get together, they often take holidays together in Holland.

Her mother was Dutch. Her father was a Yorkshireman, and a chef in the Merchant Navy. They met in Rotterdam - and laid the

The couple have four children, of whom the youngest (Philip), now aged 30, became the youngest-ever member of ASBAH's national executive when he was 18.

Hull ASBAH was formed 26 years ago. Charles's work as a higher executive officer with the DSS helped clinch many a benefit. He continues to sort out members'



foundations for many return visits to the tulip fields!

Gerritje and her husband, Charles, met while he was in the British Army. They then settled in Hull, which a daft local government reorganisation took out of Yorkshire and put into Humberside 19 years ago.

application forms.

Don't get the wrong idea about Gerritje. She does not point Hull ASBAH across the North Sea for their holidays all the time. Thirty eight members and friends have just come back from a summer break in Majorca! ■

PRODUCT NEWS

Sitting comfortably and feeling better

Ashley Healthcare Ltd of Birmingham are specialist manufacturers of a range of 'BetterCare' easy chairs which include 'prescription built' armchairs for people with special needs. Recently, their skills in bespoke chairs were put to the test when they were asked to make a chair for a seven foot man of 22 stones with a chronic spinal disability.

Mr Berg had been unable to find a chair that could give him the extra height, depth, width and lumbar

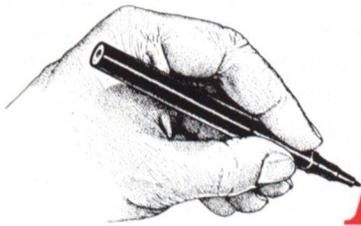


Mr Berg tries out his specially made chair from BetterCare whilst a member of Ashley Healthcare staff takes the opportunity to sit for a moment in another chair made for a customer half his size!

support that he needed. Now he has a chair which is some 29 inches larger than standard and he has "never been so comfortable in all my life".

"We take great care to consider individual needs and will work closely with therapists, too, wherever possible", says Alan Lambert, managing director of Ashley Healthcare. "We are finding that this service is of tremendous help to physios and occupational therapists."

Ashley Healthcare Ltd., 31 Speedwell Road, Birmingham B25 8HU. Tel:021 772 6235



Letters



I would like to comment on the article about us, "A Parent - In Sickness and in Health" in LINK June/July, and your editorial OPINION on it. Firstly we did not go to live in Nottingham - we live in London, but were fortunate enough to contact our wonderful surgeon, now based in Nottingham, but who had worked with paediatric neurosurgeons in Toronto before we contacted him in Britain. I would also like to point out that the money for us to go to North America was raised by friends, well-wishers and various charities; financial support without which we would have in no way been able to afford to pay for the treatment Judith underwent there.

The article cannot convey the whole complex series of operations and phases of illness - there were times in the early years when Judith was comparatively well, until she developed 'slit' ventricles. Most parents in our position would have inevitably built up a knowledge of their child's illness, and what symptoms to watch for. Each case is different and the main lesson one learns is to have the confidence to question, or to ask for a second opinion if one instinctively feels that something is wrong. The link with ASBAH was, for us, vital for information and support.

The patient, naturally, is ultimately in the hands of the surgeon, who has to decide what actual treatment to give - the decompression could only be done at the right moment - and we were lucky to find the right surgeon at the right time, and to have an excellent relationship with him -

also an important factor to put patient and family at ease.

Abe Hayeem, Edgware, Middlesex



Your readers will be interested to know that a group of five of the young people with mixed disabilities who took up residence in the new Sheffield ASBAH and Sheffield Association for People with Cerebral Palsy housing complex Stothard Court (*Keys of the Door*, LINK June/July p.8) came for a five-day course at Five Oaks in order for them to gain confidence and experience in the activities for daily living, prior to moving into their own flats.

One of these members returned for a month's extended stay in order to gain further advice and assistance in planning routines and strategies which would help to ensure a successful transfer from living at home to living more independently and running a flat.

Another member stayed at Five Oaks for three weeks in order that a detailed assessment could be made on physical abilities and needs.

This is an example of the very positive and useful role that Five Oaks can play in the development of a young disabled person; and many students with spina bifida and/or hydrocephalus have been helped to make more realistic decisions for their future through experiencing at first hand the daily requirements and activities needed for independent living and flat life.

E. Mary Barton, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire LS29.



It was so nice to read the letter about the little girl of three years using intermittent catheterisation (LINK April/May, p.18). I am 65 and was introduced to the procedure last year. It has changed so much for me and relieved my worries. I feel I can go anywhere now without problems.

I have found public loos difficult. Disabled ones are usually shut, but have now heard I can purchase a key.

I would like a support group for ISC users - there must be little problems other than medical ones that could be helped. Perhaps we could have opinions on the subject. Or a helpline just to have a talk with someone who understands?

Lorna Grigg, 198 Elgar Road, Reading RG2 0BN

Well-woman services:



I am looking into whether disabled clients are offered the opportunity to take up well-woman services, especially smears. I would like to hear from anyone who may know of any special services for this client group.

Carol Singleton, GP audit facilitator, Kirklees MAAG, 68 Wibsey Park Avenue, Wibsey, Bradford BD6 3QD. Tel: 0484 451520 or 0274 603482.

When a child dies

In a future issue of LINK we are planning to consider the subject of bereavement - in particular the loss of a child before, at or shortly after birth. Do you have an experience which you feel able to share with readers? Were you given the support you needed; were you allowed to grieve?

Please write to Jeanette Dixon, Editor, LINK, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

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When booking, check to make sure the accommodation suits your particular needs

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