Association for Spina Bifida and Hydrocephalus/ASBAH 20p

March/April 84



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Association for Spina Bifida and Hydrocephalus/ASBAH

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

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

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Ms Siobhan Rowe, BA, Dip HA

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

Information Officer: Miss B Holland

Link Editor:

Mrs Susan Gearing

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

The Access Committee for England

SINCE THE National Health Service was launched in 1948 excellent rehabilitation services have been available to any patient without cost, and this service supplemented by the rapid advances in technology suggests that any disabled person should be able to achieve a very high degree of mobility and independence. Unhappily in practice we find that disabled people are still frustrated to an unacceptable degree by environmental and attitudinal barriers in the community.

An attempt to legislate for better access for disabled people through the Chronically Sick and Disabled Persons' Act of 1970 failed because of the inclusion of the phrase '... in so far as it is in the circumstances both practicable and reasonable', and one sometimes feels that practically any reason has been sufficient to avoid compliance with this Act. The Silver Jubilee Committee on Improving Access for Disabled People did excellent work during 1978 then in its final report made a strong recommendation that permanent Access Committees should be set up in England, Scotland, Wales and Northern Ireland. This suggestion was further endorsed by the CORAD Report following the International Year of Disabled People, and in 1983 the Minister for the Disabled at that time, Mr Hugh Rossi MP, announced that an independent Access Committee for England was to be set up by the Centre on the Environment for the Handicapped with funding from the

The present Minister for the Disabled, Mr Tony Newton MP, has implemented the decision and the first full meeting of the Access Committee for England will be held this month — March.

The Committee will have about 25 members many of whom will have physical or sensorial handicaps together with professional architects, and planners and some with experience of the construction industry, fire and building regulations. The Committee will have an office in London with a full time Access Director and supporting staff but members of the Committee will come from all parts of England.

Before the Committee was constituted a consultation letter was widely circulated amongst organisations of disabled people and others involved in some way with the disabled. The analysis of the many replies received will be invaluable to the new Committee to determine priorities for action.

It is already clear that there are three major issues to tackle which form the basis of almost all the problems disabled people face. We must make sure that no new buildings are erected unless they comply with the recommendations or standards necessary for disabled, blind and deaf people. This will mean not only ensuring that the plans submitted for approval are satisfactory, but also checking that when the building is completed it is completely functional for disabled people and the design has not been spoilt by some addition, omission or thoughtlessness during construction.

The Access Committee will want to introduce a programme to improve access to existing buildings and the built environment — with particular emphasis on replacing the ubiquitous pavement edges with ramped crossings, and trying to ensure pedestrianisation schemes do not prevent reasonable access for disabled people.

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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.

ASBAH moves to new offices

ASBAH is moving . . . but only just across the road.

From this month (March)
ASBAH National Office will be at
22 Upper Woburn Place, London
WC1H 0EP. This is directly opposite
Tavistock House, and therefore
should be easily found by visitors.

ASBAH is occupying offices on the ground and lower ground floor of the building, and they are accessible to visitors in wheelchairs.

The move will give ASBAH much needed extra space at an economical rent for central London. It will make it possible to expand the tele sales operation which has proved so successful.

The telephone number remains the same: 01-388 1382, and ASBAH looks forward to welcoming you.

FRONT COVER PHOTO

SARA-ANN CARTER, 21, outside the entrance to the Acton Scott Working Farm Museum, near Church Stretton, Shropshire, where she is a secretarial volunteer.

Sara-Ann of Craven Arms, Shropshire, has recently been involved in helping produce a report* on the facilities for wheelchair visitors to the Farm Museum. It looks at mobility around the site, facilities, the displays, exhibitions and demonstrations, and makes various recommendations for improving the museum for the disabled visitor.

Acton Scott Working Farm Museum demonstrates life on a Shropshire upland farm before the introduction of the petrol engine.

The Farm Museum is situated 17 miles south of Shrewsbury or 14 miles from Ludlow on the A49. Open April-October, Mon-Sat 10.00-17.00, Suns and Bank Hols 10.00-1800. Adults £1. Children 50p. For more information ring 069-46 306 (Marshbrook).

*For a copy of the report — "The Wheelchair Visitor and Acton Scott Working Farm Museum", write to: Shropshire County Museum Service, Wenlock Lodge, Acton Scott, Church Stretton, Shropshire SY6 6QN.

• Sara-Ann's mother has written to LINK in this issue — see page 6. Photo: Shropshire Star.



Young members of the Belfast local association, parents and friends with Northern Ireland and Manchester United footballer Norman Whiteside. The occasion was a five-a-side football tournament. It was organised by the Royal Ulster Constabulary at Stranmillis Sports Centre and Belfast members of ASBAH were invited as VIPs.

Sporting Anna

DESPITE severe disability, 10-yearold Anna Williams is a 'real sport'. She is pictured with prizes that she won recently in two sporting events.

At the Welsh Games for the Disabled, Anna, who lives in Aberdare, Mid Glamorgan, won first prize for the wheelchair light ball throwing competition. She won the trophy, presented by Delta Airlines, for coming first in the wheelchair and pusher race at a fun day at Gatwick Airport organised by the Golden Lions Children's Trust.

Anna is a pupil at Pentwyn School for the physically handicapped in Cardiff. She loves listening to music,



going to discos, and is a member of the 11th Aberdare Brownies. **Photos: Aberdale Leader.**



Saving up £1,000 takes quite a bit of doing, but its something that Mrs Lammas does willingly in order to help others. She holds small fund-raising events at her home to which elderly or lonely people in the neighbourhood are invited. The money is then put away until there is a tidy sum which is then presented to a voluntary organisation. This year she chose the Staffordshire local association, and the photograph shows Mrs Lammas (right) after handing over the cheque to Miss Elizabeth Woodhouse of the Staffordshire local association (left), aided by an official of the National Sports Centre in Nottingham where the presentation took place.



TWINS, Jemma and Jodie Parkinson make their second appearance in LINK. They were featured on LINK's cover Sept/Oct 1983 when we announced the happy arrival of two healthy baby daughters to Jackie and Philip, both members of Greenwich local association. Jackie has spina bifida and gave birth to the twins five weeks prematurely on June 15.

The twins were 7 months old when this picture was taken by the local newspaper group, the Mercury. As you can see they are both growing into beautiful, healthy little girls.

After several weeks of hard work coping with them both, Jackie and Philip's verdict still is "They're terrific!"

Jackie said "Of course we will face problems but we can give them what they need — loving, clothing and feeding".

Photo: Mercury Group, South-East London.



JACKIE Stacey, 19, a member of Sussex Association, and Gary Mercer, who were married at the end of January at Shoreham Baptist Church.

Jackie and Gary met at St Giles home for the disabled in Lancing where Gary was working as a care assistant. They became engaged in 1981.

Congratulations to this young couple, and very best wishes to them in their life together. They have a home of their own, a specially adapted bungalow built by the Disabled Housing Trust at Burgess Hill in Sussex.

Photo: Brighton Evening Argus.

Study Day for parents on the Education Act

AS MENTIONED in the last LINK, the ASBAH Study Day on the implication of the 1981 Education Act was held in London on Saturday, 18th February.

It was encouraging that approximately 40 parents attended, and they seemed to think the effort very worthwhile.

The speakers at the conference were Peter Newell, author of the ACE Special Education Handbook, who gave an explanation, in layman's language, of the legal framework of the Act, and Philippa Russell of the Voluntary Council for Handicapped Children, who elaborated upon the practicalities of the Act and the implications faced by parents.

During the afternoon there was given an Open Forum and Panel Discussion. The panel comprised Hilary Cane, Head of Richard Cloudesley School, Islington; Albert Reid, Senior Educational Psychologist, ILEA; and Dr Maria Roe, Senior Staff Inspector for Special Education ILEA.

Parents certainly did not hesitate in taking the opportunity to ask questions of the experts, and, in summary, the Chairman, Alec Macpherson, (Head of Lord Mayor Treloar College) said that the day had been of great benefit to both parents and professionals.

ASBAH is planning further study days about the Act in other areas of the country. Details to be announced later.

However, in the meantime, please don't forget ASBAH is there to assist with any problems you face in connection with the new Act—if you don't tell ASBAH it can't help!

New housing project: leasing a council house

LOCAL ASSOCIATIONS might be interested to hear of a simple, yet effective, housing project started by the Cheltenham and District Association for the Disabled.

As part of a six project scheme started during IYDP, they have leased a standard family council house, in order to house three people with disabilities, who might otherwise find it difficult to obtain accommodation.

The costs of conversion work, which included widening doorways and installing a lift were shared by the Association and the housing department. The three tenants have their own rooms and share cooking, washing and lounge facilities. There is also a guestroom. The housing department are also contributing to the cost of providing a downstairs shower and utility room.

Though the residents are tenants of the Cheltenham Association, the housing department is still responsible for the usual repairs and upkeep of the property.

Advantages of the project are that it does not involve large capital costs, and in being amongst ordinary housing has features which many people with disabilities really value.

SIOBHAN ROWE

Accommodation & Development Officer

Access

Continued from page 3

The third and perhaps most difficult problem will be to try and overcome the attitudinal barriers which account for many of the cases of discrimination against disabled people seeking employment or community activities. An intense sustained programme of education must be launched at the professionals and the general public to help to overcome unjustified prejudices towards disabled people.

The Access Committee for England will work closely with all other groups involved in helping disabled people, with Members of Parliament, Government Departments, the Access Committees of Scotland, Wales and Northern Ireland and the All Party Committee on Disability of the European Parliament.

The Committee cannot work, however, without the full support of disabled people themselves, and a high priority must be to ensure that there are active Access Groups working closely with local authority Access Officers throughout the country. I sincerely hope that all members of ASBAH will become involved in their own local groups where they can give invaluable help.

Disabled people know their own local problems and by getting together can often solve them, but if not the Access Committee for England is now available to help both groups and individuals who need extra support or advice. Our office is: Access Committee for England, 126 Albert Street, London NW1 7NF, Tel 01-482 2247.

We look forward to hearing from you.

ARTHUR GOLDTHORPE OBE Chairman, Access Committee for England

Arthur Goldthorpe, who is himself in a wheelchair, is Chairman of Yorkshire Association for the Disabled, and a good friend of ASBAH. He is a keen photographer and LINK readers will remember his photographs accompanying the article on Israel (LINK May/June, 1983).

In brief

- ACE INFORMATION SERVICES has produced a useful information sheet 'Education to 19—Your Rights' which outlines the duties of your local education authority to provide full-time education for young people aged 5-19 years as they ask for it. Available from: Advisory Centre for Education, 18 Victoria Park Square, London E2 9PB. Tel: 01-980 4596.
- "OPPORTUNITIES FOR THE DISABLED" is an employment agency which deals specifically with disabled people. Branches are in London, Birmingham, Sittingbourne, Manchester, and Leicester. If you would like the full addresses contact Beverley Holland at National Office.
- THE YOUTH TRAINING SCHEME is now open to disabled young people up to the age of 21 (instead of only those of age 17 or 18). In a written statement the Minister of State for Employment announced that the eligibility rules would be extended for disabled young people.
- ANOTHER COURSE on Spina Bifida and Hydrocephalus is being held in Sheffield this year on 4-6 April. It is designed for general and community paediatricians, physiotherapists, social workers and associated professionals.

Details from: Mr A E MacKinnon, FRCS, Subdepartment of Paediatric Surgery, Children's Hospital, Western Bank, Sheffield S10 2TH. Tel: 0742 71111.



LOTTOTO

THE POINT I wish to make as a mother of a 20-year-old spina bifida is that some 18 years ago parents were being told be 'realistic'. OK I take their point, but after 20 years of rearing a disabled daughter perhaps the 'powers that be' should be realistic.

Some five years ago (before leaving residential school) it was not 'realistic' for Sara to attend a Further Education College which catered for abled bodied students only, and was situated some eight miles from home. (Usual obstacles being put in her way, ie transport, fire risks, no ramps, etc, etc.)

It was explained that Sara had been away from home for the whole of her school life, some 10 years, and we had a house which had been converted for use for wheelchair users. Why should she not come home? The LEA were not too happy, but when I asked for Sara's wishes to be considered for just half a term, if only to prove the LEA and other doubting Thomas's right, it was agreed she should attend mornings only.

Sara took a secretarial course

Local Authorities should be 'realistic'

passing several examinations and although a great deal of time was spent in hospital undergoing several valve operations we all agreed College had been a success so much so that Sara stayed for an extra year to catch up on studies.

When a Careers Officer called to see Sara she expressed a wish to work with animals or computers. The first Careers Officer pointed out to Sara, eyeing her crutches and wheelchair, that animals would be impossible. I suggested that in view of the unemployment in the country, perhaps Sara could do some kind of voluntary work, the reply was . . . 'the Unions will be uncooperative'.

A year or two passed and another Careers Officer called and Sara was keen on computers. The reply was 'No one in this area has a computer'.... We explained to the officer that surely all areas would be computer-minded in years to come. (Needless to say I lost my cool!)

Sara now works voluntarily whilst the recession continues — at the Acton Scott Farm Museum. This helps from a medical point of view as she really could not cope with full time work at present, but at the same time Sara is an audio typist and is gaining useful office experience.

To conclude, we are now quite friendly with the first Careers Officer and in fact Ludlow College put up ramps for Sara, which have been used by two other spina bifida and hydrocephalus students who were confined to wheelchairs.

So please LEAs and Careers Officers do not daunt our teenagers before exploring all avenues, be *realistic* and realise the world is a kind place and society will help where ever it can. After all the deaf dance feeling the musical vibrations through the floor, and for those of us who watch the TV series "Knight Rider" the blind could drive!

Mrs J Carter, Craven Arms, Shropshire.

Sara is pictured on the cover of this issue of LINK.

The subtle problems of learning to drive

FIRST OF ALL I would like to congratulate Mobility Information Service and Lions International for extending their service to the disabled public. I am sure that their assessment unit will be in great demand and particularly in schools for the physically disabled.

It was stated in the announcement in LINK (Nov/Dec, 1983) Would-be drivers put to the test—that this "unit was capable of coping with a wide range of physical handicaps". This was obviously said advisedly.

Many of our spina bifida/hydrocephalic youngsters have other more subtle problems which could influence their ability to drive, quite apart from their physical disablement. I would just like to sound a cautionary note to the effect that the physical difficulties are not the only ones to overcome when learning to drive. Problems of learning and judgement of space, distance and speed, may result in prolonged tuition and often frustrating results. It is necessary to be aware of any of these problems and also for the driving instructor to be told and, where possible, advised how to deal with them.

If you feel that your driving instructor does not appreciate your difficulties, he can obtain further information from Banstead Place Mobility Centre which runs courses for driving instructors.

If there are any other queries on mobility out of doors contact: Leonie Holgate, Banstead Place Mobility Centre, Park Road, Banstead, Surrey. Tel: Burgh Heath 51674.

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Kielder caters for all the family

A NEW family adventure centre is taking shape on the shores of Lake Kielder in Northumbria. It will provide all-year-round outdoor, indoor and countryside activities for the disabled and their families.

It is another Calvert Trust venture. The Northumbria Calvert Trust was born in November 1981 and is a separate legal entity from the original Trust at Keswick, although closely related.

The objectives at Kielder will be rather different from those at Keswick. It will primarily attempt to serve a yet unfulfilled need — that is to provide adventure holidays for disabled people and their families. The intention is that complete family groups should holiday together knowing that the disabled person will have proper facilities and that the family can participate together in all activities.

The boathouse complex is already finished, and the main centre should be open 'for business' about the end of July — a little later than anticipated partly because of the appalling weather.

The Northumbria County Council has already established at Low Cranecleugh on the shores of Lake Kielder an educational field pursuits centre and they have enthusiastically co-operated with the Northumbria Calvert Trust to develop the plans for the new Adventure Centre.

Kielder Lake is the largest man-made lake in the largest man-made forest in Europe, and provides a unique opportunity to establish an Adventure Centre with wonderful water-based activities as well as activities associated with a great forest.

The accommodation will be suitable for all disabled people. There will be transport to enable them to get safely from the centre to the lakeside for boating and canoeing and to move freely around the forest.

As at Keswick, understanding instructors will have experience of the special techniques necessary to introduce disabled people to outdoor activities.

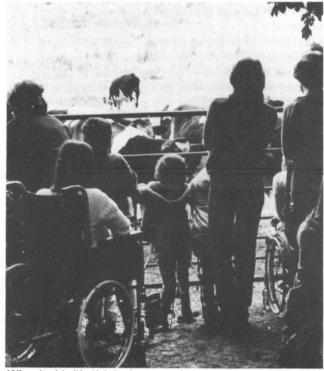
Full details can be obtained from Mr Jim Wainwright, the Warden, Low Cranecleugh, Near Falstone, Northumberland. Tel: 0660 50232.

Opening up the South of France

PHYSICALLY handicapped people should be able to enjoy an independent holiday in the South of France with an emergency back-up service. This is the intention of a Dutch organisation, Stichting Vakantie en Handicap.

It has a centre on the Cote d'Azur providing an information service, backed up by a 24-hour emergency service and it offers to organise help such as medical treatment or the provision of a helper or taxi service if required.

For more information contact: Dr W A Godefroy Stichting Vakantie en Handicap, Villa Serenata, Domaine de la Ferriere, 83480 Puget-sur-Argens, France. Tel: (94) 45-60-95.



What is this life if full of care we have no time to stand and stare. . . . Youngsters from Sussex Association finding time to stop and gaze while on a weekend at Felbury House.

Photo: Philip Ridler

Beautiful Finland beckons

FINLAND offers beautiful scenery, open spaces and friendly people and if you are interested in a holiday there you may like to find out more about a holiday hotel on the shore of Lake Saimaa, fully adapted for wheelchair users and other disabled holidaymakers.

The Marjola Hotel is administered by the Association of Handicapped People of Southern Saimaa, and is on the lake shore, 6km from the town of Lappeenranta. It provides boats, fishing and archery equipment and a wide range of sporting facilities all free of charge.

The hotel can accommodate 50 people in rooms with 1-3 beds and is open all year round for groups, and between mid June and mid August for individuals. Self-catering facilities are also available.

For information contact: The Manager, Etela-Saimaan Invalidit r.y, Kauppakatu, 58-60, 53100 Lappeenranta 10, Finland.

Bird watching made possible

BIRD and wild-life watching facilities are increasingly being opened up to people in wheelchairs or with impaired mobility.

The Royal Society for the Protection of Birds (RSPB) issues a free leaflet 'Opportunities for Disabled People to visit RSPB Reserves'. It indicates to what extent a disabled visitor may be able to gain access.

Write to RSPB, The Lodge, Sandy, Beds SG19 2DL. Tel: Sandy 80551. For general visiting rules there is another free leaflet 'Reserves Visiting'.

Five Oaks provides holiday specials

SPORTING activities, fishing, cookery, fashion, and music and drama are some of the subjects featured in holiday courses at ASBAH's centre in beautiful Wharfedale, Yorkshire — Five Oaks.

The Staff at Five Oaks offer a warm welcome to anyone with spina bifida and hydrocephalus, and the house itself is comfortable and accessible. It is situated in Ilkley which is easily reached by British Rail.

If you would like to know more about Five Oaks and its holiday courses contact: Mr Jim Stanton, Five Oaks, Ben Rhydding Drive, Ilkley, West Yorkshire. Tel: Ilkley (0943) 609468.

Threshold eliminates the gamble

THRESHOLD Travel aims to take the gamble out of choosing a holiday abroad for someone who is disabled.

Its brochure caters for the needs of the physically handicapped traveller who, accompanied by family or friends, wishes to take a conventional holiday without encountering the anxieties they usually associate with holidays abroad. There are some UK holidays, too, available through Threshold.

A good range of hotels and self-catering accommodation has been chosen and information given about accessibility, etc. The brochure claims: "The hotels that are featured are the ones that cater best for your special needs. Price was not the first priority — although we believe that all our prices are keenly competitive."

For a free copy of the brochure fill in the form in the Threshold advertisement on this page.

Five family cottages on offer

THE STACKPOLE Holiday Adventure Centre, surrounded by beautiful National Trust country in Wales, is an ideal place for a comfortable self-catering family holiday. Five family cottages, tastefully modernised and furnished and suitable for holidaymakers in wheelchairs are now fully operational and are available at subsidised rates: October to March, £40 per week; April, May, Sept, £60 per week; June, July, Aug, £80 per week. Prices are for each cottage.

ASBAH is one of six charities involved in setting up the trust. The others are Barnardo's, The Muscular Dystrophy Group of Great Britain, PHAB, Mobility International, The Shaftesbury Society.

For more information and bookings, contact the Project Director: Alun Jones, Reaches Riant, Lawrenny, Nr Kilgetty, Dyfed. Tel: Carew 604.

Sharing the joys of camping

CAMPING can offer greater opportunities to travel unhampered by steps or hotel bills. Camping can offer a unique opportunity to become close to the countryside around you. Almost everyone who is disabled, no matter what type of handicap they have, can become an active camper with just a little help from friends or family, and some forethought.

With Camping for the Disabled we hope to encourage established disabled campers to come together to share experiences, pool information and ideas, and help those who have never had the opportunity to try camping to do so.

If you are disabled, or your family has a handicapped member who enjoys camping, be it under canvas, with a caravan, or in a luxury motor home, why not join with us to help spread the joys and achievements that outdoor life can bring to someone with a disability.

Already we have several very successful camping events behind us, and our new Weekends Programme contains a wide choice of camping venues from the Northumbrian Hills to the glories of Devon.

The Club also gives details of campsites in Britain and Europe.

If you would like further information, then please contact me:— David Griffiths, Camping for the Disabled, 20 Burton Close, Dawley, Telford, Shropshire TF4 2BX, or telephone 0743 68383 during office hours. The membership fee is only £2 per year for up to five members of a family.

David Griffiths



Cardiff, London, Oxford and Cambridge are centres for ASBAH research

Research into all aspects of spina bifida and hydrocephalus is an important part of ASBAH's work. To keep LINK readers 'in the picture' here is the current list of research projects being sponsored by ASBAH.

Mr Z Ralis, MD, FCCS, Welsh National School of Medicine, Cardiff

A three-year study to look at why children with spina bifida tend to have more fragile bones than other children and are therefore more susceptible to fractures and deformity.

Professor K M Laurence, Professor of Paediatric Research, Welsh National School of Medicine, Cardiff

A follow-up to previous research into the effects of the introduction of pre-natal diagnosis on the reproduction history of women who are at increased risk of neural tube defects.

Dr R Bayston, M Med Sci, PhD, Institute of Child Health, London. Two Projects.

- i. A three-year investigation into the feasibility of non-surgical management of shunt colonisation in subjects with hydrocephalus through the use of antibiotics.
- ii. A two-year study to investigate the malfunction of valves used in shunting systems to control hydrocephalus and to ascertain how this can be prevented.

Dr A J Copp, MA, D Phil, (Prof Polani's Unit), Paediatric Research Unit, Guy's Hospital, London

An experimental investigation of neural tube defect in the mouse embryo in order to determine whether spina bifida can be corrected by grafting normal tissue into affected embryos prior to the appearance of the defect using curly tailed mice found to be particularly susceptible to neural tube defects.

Dr G Hunt, Addenbrookes Hospital, CambridgeA follow-up of a cohort of babies treated unselectively.

Prof N J Wald and Dr A C Turnbull, Gibson Labs, University of Oxford

Collaborative Acetylcholinestearase Study — diagnostic tests for the antenatal detection of neural tube defects — an alternative to AFP testing which will aim to reduce the incidence of false positives/negatives.

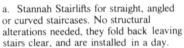
Professor K M Laurence, Professor of Paediatrics, Welsh National School of Medicine, Cardiff

The effects of high daily intake of folic acid. A study in response to the Medical Research Council Trial and other vitamin trials to ensure that high doses of folic acid are completely safe.

CONGRATULATIONS TO 13-year-old Colin Draper of Hull and District Association who won first prize in a story competition organised by Radio Humberside. His story was read out on the air, much to the delight of the Association members.

Push button solutions to stair problems

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THE DISABLED Living Advisers handle a large number of enquiries concerning a wide range of subjects. However, there are particular problems about which they are constantly asked.

The DLA's hope through occasional pull-out articles in the centre pages of LINK to cover some of these. The first articles are concerned with:

CHILDREN'S FOOTWEAR AND INTERMITTENT CATHETERISATION

If you have any suggestions for areas like these to be covered in future editions, Mary Small and Andrea Robinson (Disabled Living Advisers) will welcome suggestions.

ONE RECURRING problem concerning footwear is that many youngsters who are naturally fashion conscious, want to wear smart and stylish shoes but cannot find any to fit. As many youngsters do not have standard sized feet, they require wider or deeper shoes or even completely different sizes of shoes to fit each foot. Here are some ideas which may help you find suitable

Buying Shoes

It is extremely important that footwear is fitted by trained staff, whenever possible. A list of suitably qualified members can be obtained from

National Society of Shoe Fitters 3 Masons Avenue, Wealdstone, Harrow, Middx HA3 5AH. Tel: (01) 427 1545.

Normal Shoes—wide fitting

Those wishing to obtain shoes from a particular manufacturer or wholesaler should contact them for the names and addresses of retailers in their neighbourhood. It must be noted that only some styles of the shoes supplied by the manufacturers are obtainable in the size/fittings range indicated here.

Clarks Ltd

Clarks make a wide range of sizes and fittings for children's shoes and will also carry out alterations and adaptations. Peter Lords are fitting specialists.

Manufacturer: Clarks Ltd, 40 High Street, Street, Somerset BA16 0YA, Tel: (0458) 43131.

Others with a wide range of fittings include:—

• K Shoemakers Ltd—including 'Kidproof' scuff resistant range:

Manufacturer/retailer: K Shoemakers Ltd, Netherfield, Kendal, Cumbria, LA9 7BT. Tel: (0539) 24343.

• Portland Shoes Ltd—'Kiltie range'

Manufacturer: Portland Shoes Ltd, Gateway Street, Leicester, Leics LE2 7DL. Tel: (0533) 556112.

• Start-Rite Shoes Ltd

Manufacturer: Start-Rite Shoes Ltd, Crome Street, Norwich, Norfolk NR3 4RD. Tel: (0603) 43841.

LINK SPECIAL No. 1

March/April 1984

Odd-Sized Pairs

The Disabled Living Advisers have heard that many people are currently buying two pairs of shoes so that they can take one of each to make a correctly fitting pair. There are other ways of getting round this problem.

BSC Footwear Supplies Ltd

BSC will give details of a forwarding letter to take to one of their branches so that an odd-sized pair of shoes can be ordered (Saxone, Lilley and Skinner, Mansfield, Truform and Freeman, Hardy and Willis). The individual sized pair of shoes will be available in 4/5 weeks at no extra charge (children's sizes). This scheme, of course, does not apply to all the styles of shoes in their range.

Address for further details: BSC Footwear Supplies Ltd. Sunningdale Road, Leicester, Leics LE3 1UR. Tel: (0533) 871355.

The following manufacturers also supply odd pairs, but, of course, there is a delay of a few weeks:

- Baby Dear Shoes Ltd, Commerce Road, Stranraer, Scotland. Tel: (0776) 2651.
- Clarks Ltd. Fitting Services Manager (address given above).
- Start-Rite Shoes Ltd. They also make shoes on adapted standard lasts (address given above).
- Kids & Co Footwear Ltd, Wollaston, Wellingborough, Northants. Tel: (0933) 664205.

Manufacturers may charge a surcharge for these services.

Odd Feet Associations

There are also various clubs which offer a matching service, pairing complimentary odd feet. The idea is mainly to partner people with someone who takes reverse shoe sizes to themselves. This, of course, cuts the cost of having to purchase 'two pairs' of shoes. A small registration fee is required.

- Shoe Mates: Send sae to: Mrs M Littleton, 13 Coney Close, Langley Green, Crawley, West Sussex RH11 70A.
- Sole Mates: This Association is affliated to SOFA which is mentioned below.

If a customer should have to wait for a partner to turn up, they will try to supply a pair of shoes from their stock of new shoes which they are building up.

They also have a list of suppliers and services of 'odd shoes'.

Children's Footwear **Problems**

For further details—enclose an sae

Sole Mates, Mrs Cross, 46 Gordon Road, Chingford, London E4 6BU.

• SOFA (Stockport Odd Feet Association).

SOFA liaises between manufacturers, retail and welfare organisations and members it has collected, circulating information on facilities throughout the country.

Affiliated manufacturers and retailers offer a discount to SOFA members buying two pairs of shoes. Again, a partner with feet the same size but the opposite way round to themselves may be found or the unwanted pair can be advertised in their journal. Membership—£1.50 per annum.

Please send sae to: Gill Evans, 17 Deva Close, Poynton, Cheshire SK12 1HH.

Obviously, the more people who contact these organisations the more likelihood of finding a suitable partner.

Made-to-measure shoes

If the youngster's feet not only differ in length but are also wider and/or deeper than the standard fittings, shoes can be made to measure on adapted standard lasts. Firms who offer this service include:



'John Locke' Shoes—Ladies' (size 1 upwards)/men's.

John Locke shoes aim to fill the gap between normal shoes and surgical boots. They manufacture and supply individual pairs of shoes made in a wide range of sizes and width fittings, and with fast delivery. The cost is approximately £50 to £60.

For children's shoes (John Locke) contact:

• Soma UK Ltd, 3/7 Moss Street,

Liverpool L6 1EY. Tel: (051 207)

These are now available through the NHS or privately.

For further information contact:

 John Locke Shoes, Frank Harvey & Co, Stowmarket, Suffolk IP14 1NE. Tel: (044) 612646.

For further details concerning other firms making shoes to measure on adapted standard lasts, please contact ASBAH, National Office.

When suitable footwear cannot be purchased by the parents there is a range of ready-made surgical footwear available which can be prescribed by the hospital consultant and supplied by the appliance officer.



Eagle Boot—Remploy

Of the ready-made, open-to-toe boots, the Eagle Boot is very popular. It is practically identical to the Piedro Boot which is imported from Holland. It provides a wellmade, good quality attractive boot, and in a full range of width fittings and half sizes. Infant size 3 to adult

Supplier: Remploy Ltd, (Medical Products Div/Orthopaedic Div), 415 Edgeware Road, London NW2 6LR. Tel: (01) 452 8020.



Wizard Boot

Preferred by many children for its 'desert boot' look, it comes in one fairly wide width fitting, and size infant to adult size 5. It has a fairly

rigid sole which many have found helpful. It has a soft upper which moulds well and forms a good fit round the ankles. It is made in leather and has striped laces. Colours—brown, red and black. Cost: Small £16.56, large £22.

Agent: R Taylor and Son (Orthopaedic), Compton Works, 49 Woodwards Road, Pleck, Walsall, W Midlands WS2 9RN. Tel: (0922) 27601.



Cooper Kid Boot

The Cooper Kids Boot is quite attractive. It comes in two width fittings—normal and wide, and three depths—normal, deep and extra deep. They have whole sizes from size 1 to adult size 5. They are a variety of colours (black, brown, beige, navy and red), and they are durable and lightweight.

For those youngsters who require extra width and/or depth but do not need the ankle support given by a boot, they also manufacture sandals and trainers in the same range of sizes, widths, and depths as their boot. Prices—size 12—£28; size 12+—£30.

Manufacturer: P R Cooper (Footline) Ltd, Seaford House, 27 Stoughton Street South, Leicester, Leics LE2 0SH. Tel: (0533) 29482.

• The Ortho Boot

The boot ranges from infant size 5 to adult size 5 plus odd sizes. It is made in dark brown leather with large brass eyelets which make it more attractive. It also looks like a 'desert boot'. It has a fairly wide fitting and can be used for children with spina bifida although it does not open completely to the toe. Sole is fairly rigid and wears quite well.

Agent: Kettering Surgical Appliances Ltd, 5 Harlesdon Road, St James, Northampton, Northants NN5 5LN. Tel: (0604) 57179.

• The Biffabout Boot—with a face lift!

This is one of the boots designed specifically with the short, wide and deep foot of the spina bifida child in mind. It comes in two depths—normal or standard fitting—is very



The Biffabout Bootee

deep but a slightly shallower fitting is available on request. Infants size 1 to adults size 9. The boot is available in soft leather or suede and has a warm plaid lining.

It is made in various colours (matching or contrasting). It is useful as a warm boot for wheelchair bound patients. Cost: £37/£47 depending on size.

Manufacturer: Ken Hall Ltd, 39 Regent Street, Kettering, Northants NN16 8BR. Tel: (0536) 516674.

• Hill Boot—Remploy (address already given)

Similar shape to Biffabout and also designed for spina bifida children with short, broad feet, but is made to order. Brown suede only. Size 0 to Adult 11. Odd sizes.



Kickabout Boots

LSB manufacture a range of children's and youth's kick-abouts in full sizes which are similar to conventional footwear and are smart and attractive.

The whole shoe opens to the toe area for easy access. For simple and adjustable fastening there is a strap and buckle at the toe, and ski hooks are fitted to make lacing easy. They have medium width and good depth and come in sizes infant 3 to adult size 11. Brown leather is the standard colour. However, red boots are supplied in infants sizes 3 to 9 and black boots in infants size 12 to adult 5.

Price approx: £22/£23.

Manufacturer: LSB Commodities, 203/4 Melchett Road, Kings Norton, Birmingham B30 3HU. Tel: 021-458 2425/4671.

Chailey Boot

These are made by a private company which is situated within Chailey Heritage's grounds. It is an attractive and well-designed boot. It is available in child size 5 to adult size 5. It is fairly wide but special widths can be made to order and the choice of depths is shallow or deep. It can be made in two tone, red, blue or brown and supplied in odd sizes.

Supplier: John Florence, Orthotic Workshop, Chailey Heritage, Rehab Engineering Unit, Lewes, E Sussex, BN8 4EF. Tel: (082-572) 2063.

Footwear Demonstration Kits

The Walking Holdall (children) or Tenderfoot Kit (adults)

The Disabled Living Foundation has assembled two large holdalls full of samples of all the ready-made orthopaedic footwear currently available; examples of the most useful footwear adaptations for common problems; temporary footwear and specially made footwear; and some commercially made footwear with special features (not included in this article). It also contains a set of slides and notes for demonstration.

The Disabled Living Advisers from National Office are planning to hire a kit and give demonstrations to any Local Associations or groups of youngsters with spina bifida or their parents who are interested.

Alternatively, the kit can be hired from the Disabled Living Foundation, 346 Kensington High Street, London W14 8NS. Tel: 01-602 2491.

WE ARE unable to cover the whole range of footwear possibilities in this article, but we do hope that people who are having difficulties will contact Mary Small and Andrea Robinson, the Disabled Living Advisers at National Office. They will welcome any queries particularly those concerning shoes for adults, and National Health Service supplies procedures which have not been covered.

Mary Small, Dip OT, SROT, Disabled Living Adviser, ASBAH, 22 Upper Woburn Place, London WC1H 0EP. Tel: 01-388 1382. INCONTINENCE, if not managed successfully, can be the most depressing and soul destroying of problems whether it be for the child, adolescent or adult.

In the past, a variety of methods of management have been implemented to try and overcome the physical, psychological and social problems incontinence creates.

People with spina bifida require constant supervision of bladder and renal function. To prevent irreversible kidney damage, urinary diversion has been the usual long-term solution. Now opinions and attitudes of the medical profession have changed since urinary diversion does not eliminate late complications and problems as originally thought—hence a need for an alternative approach.

For many, intermittent catheterisation offers such an alternative.

The aims of intermittent catheterisation are to render the child/adult dry to allow social acceptance and to interfere as minimally as possible with normal anatomy and physiology.

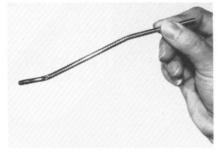
Not everybody is suitable for intermittent catheterisation and hospitalisation for a day or two may be necessary to assess accurately bladder function i.e. type of bladder, bladder capacity, residual urine volume, length of dryness period.

A good capacity bladder with adequate sphincters is essential. The person with overflow incontinence often enjoys success.

Intermittent catheterisation is a non-sterile procedure—and, indeed, in many cases has reduced the incidence of urinary tract infection because the bladder is being emptied completely and regularly.

It is a very simple procedure and can be learnt by children as young as 5 or 6 years of age. The catheter is inserted into the bladder; the bladder emptied and the catheter removed. This is repeated at intervals of 2/3 hours, the time being adjusted to achieve dryness in between catheterisations.

In very young children the parents are taught the procedure. The same catheter can be re-used for a week or more, care being taken to clean it adequately, i.e., washing it in soap and water and rinsing thoroughly. It



Metal catheter



Practising catheterisation on a specially adapted doll.

Intermittent Catheterisation

should be kept in a dry, clean container or polythene bag until used again.

Some people soak catheters in a mild antiseptic solution such as Saylon or in Milton overnight.

Metal catheters are also available and last indefinitely.

Intermittent catheterisation can enable teenagers to enjoy a better social life and by keeping them dry helps heal pressure sores, napkin rashes and eliminate smell. Many girls, when wearing calipers, have difficulty catheterising themselves



Sitting astride the toilet is one position for carrying out the techniques of self catheterisation.

Downs Surgical has brought out this mirror-torch to help girls with intermittent self-catheterisation.

Many girls have difficulty indentifying the relevant parts of the body because of lack of sensation, and therefore they must be able to see what they are doing.

The mirror-torch combines the two essentials—a mirror and adequate light, and it will fit into a handbag. It is battery operated and costs £ 10.38 from Personal Products Division, Downs Surgical, Church Path, Mitcham, Surrey CR4 3UE (01-468 6291).

because they are unable to part their legs sufficiently, but Aids Centres, such as the one in Newcastle upon Tyne, are trying to overcome such difficulties with appropriately placed hinges, etc.

Success also depends on the youngster's readiness to learn (a very individual matter), manual dexterity and emotional readiness and motivation.

Parents or individuals who think this method of managing urinary incontinence may suit them should consult their paediatrician/urologist.

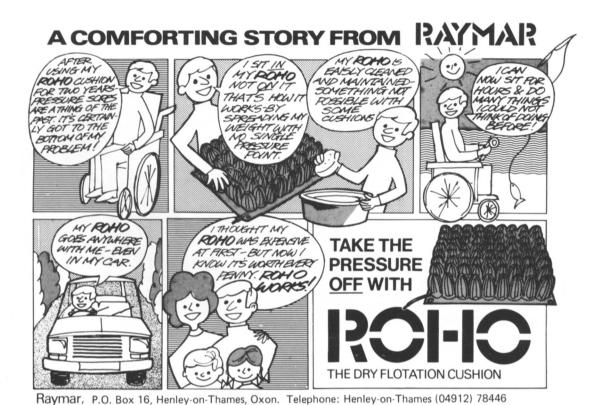
For your information, Scott and Nelaton catheters are now available in a variety of sizes on prescription (since 1.12.83).

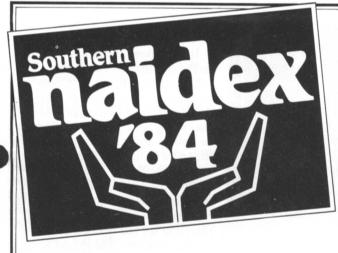
Metal catheters (only for females) can be obtained from Chas. F. Thackeray, P.O. Box 171, Park Street, Leeds LS1. Prices start at approximately £10. I have more literature available on these.

If you have any specific queries, or are already practising intermitent catheterisation, please do contact me at National Office.

Andrea Robinson, SRN, SCM, HV, Disabled Living Adviser.







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ORLAU takes a big step forward

by J H Patrick, FRCS Consultant Orthopaedic Surgeon

A COMMENT from ORLAU (Orthotic Research, and Locomotor Assessment Unit) seems right for this edition of LINK because we wish to inform you about some important advances that we are making in Oswestry at the Orthopaedic Hospital.

Parents who have children with spina bifida are at once shocked, horrified and pessimistic about the future. But after the first anxious months, the orthopaedic surgeon usually becomes involved and sees the child. He will explain that because of the usually severe damage to the nerves which work the legs, various paralyses have developed from birth

In "lower level" spina bifida (eg at a sacral level near the lowest part of the spine) often only a few of the nerves to the muscles which work the feet are involved. Usually then, simple splints made of polythene or even below-the-knee irons are required to achieve independent walking.

If the level of the spina bifida lesion is higher up the spine, greater and greater levels of handicap will occur. Those children born with lower chest level (thoracic) paralysis usually will have non-working hip muscles (at the root of the limb).

It has been said for years that this group of children will not be able to walk. Parents, physiotherapists, doctors and nurses are often the perpetrators of this rather forlorn message.

This opinion, however, is well founded in many places since, although the walking splints given are made in the 20th century they are



Fig 1. Above and below – The Swivel Walker.



constructed to 19th century designs and the splints are not good enough to allow effective walking.

ORLAU began its important work in 1975 under the guidance of Mr G K Rose, an orthopaedic surgeon dealing with a spina bifida population that was growing in Shropshire and along the Welsh borders. He saw that a Victorian splint cannot easily work for those children with hip muscle paralysis and he modified a device invented for thalidomide affected children (without limbs) to produce something now called the Shrewsbury Clicker splint.

This worked well and the idea has been further developed and refined. The end result is now the ORLAU Swivel Walker (see fig. 1). It has a nice open front aspect to allow the child to get in and out of it by himself, from the wheelchair or the floor, without any assistance.

It also allows the hands to be free, so the young child can stand at a table and learn to use both hands for all the exploration tasks usually undertaken at an early age. We think that when other children are learning to walk at approximately 14 months, the spina bifida child can do the same in the Swivel Walker.

Over the next year or so the child will learn how to move in the Swivel Walker, by rocking from side to side, and for the next 4-5 years we suggest that the child should have all the joy of experiencing independent movement around the home, at playschool and elsewhere.

About the age of six we think that quite a high percentage of these children can graduate to our "second generation" of splints—the Hip Guidance Orthosis—(fig. 2). This allows walking which looks much more normal.

This is achieved by what we call reciprocal walking, by which we mean putting one leg in front of the other and transferring the body weight from one leg to the other. This splint (orthosis is the medical

word for splint) seems very successful indeed for our Shropshire patients. It has been rapidly developed in the last 2-3 years and is now becoming available to many other children in Britain through the advent of special centres which we in ORLAU are setting up.

Here doctors, nurses, physiotherapists and orthotists (a splint fitter) become part of a team which can measure, fit and use the splint, to allow one third of these severely handicapped children to walk nearly anywhere at will (we call that community walking). Some children are so badly handicapped that they cannot walk out of their house or out of the school, but they can be kept out of wheelchairs and allowed to walk easily without exhaustion in their school gymnasium.

Some may ask is there any point in this effort over the long term? If these children inevitably are going to end up sitting in a wheelchair in their teens, (and thus for the rest of their lives), why try so hard to keep them walking during childhood and early adolescence?

The answer is that standing and walking improves bladder and bowel function and keeps the bones strong and to be upright is a marvellous psychological boost.

We now know of another reason. I believe we can challenge the



Fig 2. Hip Guidance Orthosis.

accepted view that Spina Bifida children *will* be confined to a wheel-chair by the age of 14. In the last year we have been able to get adult paraplegics walking in a larger version of this Hip Guidance Orthosis — the Parawalker (fig. 3).

These adults have been paralysed by severe accidents, but instead of contemplating a life in a wheelchair, we can offer some of them now the opportunity to walk in splints. Although these are very early days in



Fig 3. The Parawalker.

a research project that we have just begun we think that in the lifetime of children now suffering from spina bifida they will be able to make use of this further research. Then like the adult paralysis patients, they will be able to consider continuing walking in the splint (parawalker), well into adulthood.

We believe therefore the future to be rosier for high level (thoracic or hip paralysed) patients when it comes to walking, than ever before.

ASBAH Survey highlights poor hospital services for the over 16s

ASBAH has been concerned for some time to learn from young people and their parents, that they are not happy about the hospital services they receive after transferring from paediatric to adult services. This concern was brought to the attention of the DHSS who asked ASBAH to provide them with further information.

A survey was carried out among young people aged 16 and over and the results showed that while many people were content with the services prior to transfer, it was a very different matter afterwards. In many instances little discussion had taken place early enough, if at all, and then had rarely included the person involved. Many people had to travel large distances and to several hospitals for treatment, and rarely saw the same doctors or other medical personnel twice. The feeling was often expressed that those who they did see had little understanding or knowledge of their conditions.

It was then decided that the problem should be looked at in more detail, so the District Health Authorities were surveyed to see if they were aware of the number of adults and children in their area with spina bifida and hydrocephalus, and if they felt that present arrangements were adequate. The results are still being analysed, but it appears that there is a vast gap between the consumers and the health authorities ideas of what amounts to a satisfactory service. In many cases health authorities had no idea of the number of people in their area with these conditions, others felt that though they provided no service themselves it was perfectly appropriate for people to travel to other health authorities who did.

In order to be aware of the wide range of provision and expertise which may be necessary, a further study is under way to look at the problems experienced by the older person with spina bifida and/or hydrocephalus.

Already, from the small number of replies received it is obvious that this group born before the improved medical techniques of the 60's and early 70's has experienced a wide range of problems, which have not always been fully understood by those caring for and treating them. When all the information has been gathered together, ASBAH will be making a strong recommendation for appropriate medical provision.

If any readers of LINK with spina bifida and/or hydrocephalus and who were born in 1955 or earlier have not received a copy of the questionnaire, then please contact Beverley Holland at National Office.





Faith Seward is the Head of a special primary

Training and Employment Committee.

The Education,

... as seen by a headmistress who is disabled

THE 1981 Education Act, following the Warnock Report, has done a great deal to help those children with special education needs. These include the majority of children with spina bifida and/or hydrocephalus. We have learnt a great deal about rights of the children — especially their right to an education suited to their needs.

May I as a headteacher give some thoughts on the subject, bearing in mind that I too am a handicapped person.

The Education Act said various things and despite popular belief it did not say several other things. We have heard of many of the things that were said but let us think of some of those other things.

The Act did *not* say that there was no need for special schools or units catering for children with special needs. There is still a need for these special schools and units and they play a valuable part in the education of some children.

The Act did *not* say that all children with special needs must be educated in the normal or main stream schools. Many of them cannot cope with main stream education. It did *not* say that all schools must be adapted for the handicapped although new buildings should be designed for the possibility of these children being educated in them.

Let us then consider the criteria for integrating the child with special needs within the ordinary school and hopefully give a little help to those thinking of the education of their child and what is the best placement for them.

Consider these points when deciding on the placement of your child.

• Is the school building (even with the addition of ramps, etc) suitable for your child? Many old Victorian buildings and many very large rambling buildings are not suitable. If a child misses one-quarter of an hour of each lesson in travelling to class he is missing valuable time for education. If he finds

movement so difficult that it tires him out physically he is not going to benefit from learning.

- Can he receive the medical/physiotherapy help he needs in an ordinary school or is his withdrawal for that (often to travel to a hospital or centre) going to mean he misses large parts of the school curriculum?
- Can he take part in the majority of school activities in a natural way or is he always going to be confined to doing something different for large parts of the day

 like eating apart from his peers and so being deprived of social contact?
- Is he going to become so 'different' from his peers that he becomes identified as 'odd' and become miserable because of this?
- Is the school going to revolve round your child to the extent that his education and that of his peers is going to be seriously affected?
- Is he going to have to be 'helped' to the extent that he ceases to have any independence?

These are problems I meet very often. Being quite obviously handicapped I have more applications for entry to the school at which I am the headteacher than most. I am expected by parents to take the handicapped because I am handicapped myself.

It often comes as a shock to parents when I tell them that I couldn't have coped in the ordinary school — and didn't. I attended a small private school with classes of 10 until I was 11.

I do take children who have special needs including those with physical handicaps but *only* if I consider they can cope and then after extensive interviews with parents and child. They come on a 'trial' basis at first to see if they can actually manage.

Children with handicaps have a lot to cope with. Please parents think of this when you consider their education. Don't fall into the trap of trying to make them so normal that they become much less than normal in a situation that they cannot cope with.

FAITH M SEWARD MBE

RECENT years have seen major changes in the way BR sets out to meet the needs of disabled travellers. This stems from a greater recognition of the crucial role transport can play in helping people with various disabilities to lead a fuller life and the particular advantages rail can offer for greater independence and personal freedom.

Even before the highly successful International Year of Disabled People in 1981, the Board had set up an advisory group, made up largely of members drawn from outside the industry and experienced in the needs of the disabled people.

The past three years have seen the Board in the forefront of change to improve matters for disabled travellers with new stations and rolling stock being designed with their needs incorporated. This will continue, bringing as it most often does, benefits to all passengers.

The major problems are, of course, a legacy of well over 2,000 stations built at a time when the needs of disabled people were not taken into account and, to a lesser extent, existing rolling stock some of which is up to 40 years old.

Stations

Now, by the end of 1984, British Rail plan, as the first part of a three-pronged campaign, to complete modification to a core system of 55 major stations so that they are totally accessible and readily usable without anxiety by people with differing disabilities.

That means, for example, providing dedicated parking spaces, ramps, unisex toilets, stairs and platform edges marked to benefit people with sight defects, and induction loops at booking office windows to help those with hearing aids. Other improvements include better signing, adaptation of lifts to passenger operation, and staff training.

By concentrating initially on these stations, BR will in a comparatively short time be providing within their overall network a core of well used stations and inter-connecting long distance trains that offer a consistently good and comprehensive service to the disabled traveller.

A programme for installation of unisex toilets at these core stations has already been agreed and other programmes are being developed.

British Rail promises an easier ride



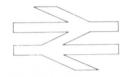
Making access easier.

Secondly, BR is making funds available to extend community involvement in improving access and facilities for the disabled at stations *throughout* the network. Local authorities, organisations or even commercial concerns are challenged to match £1 for £1 the money BR will make available for such station improvements.

Though early days yet, a number of initiatives are already under way with local authorities — ranging from dedicated car parking spaces, adaptation of lifts and building of ramps to provision of special toilet facilities.

Thirdly, BR is seeking sponsorship from commercial companies or indeed anybody for provision of facilities for disabled people at stations. Recent examples include purchase of wheelchairs, provision of a unisex toilet at a local station and some offers to provide induction loops at booking offices. There is considerable scope for such initiatives.

The needs of the disabled travellers are being incorporated into new rolling stock designs and, increasingly, stock being extensively refurbished.



Modern InterCity coaches incorporate grab handles, wide access (often automatic) doors, and a removable seat at one end of the 1st class coach allowing access for most people in wheelchairs. The passenger in a wheelchair is charged a special fare of half the ordinary second class fare and this reduction also applies to a companion.

In modern InterCity 2nd class coaches a table has been removed from one group of seats nearest the entrance and the toilet.

New sleeper coaches include, amongst many improvements, interconnecting doors between pairs of compartments.

New suburban trains and crosscountry trains currently being constructed take into account the needs of disabled travellers with lower steps, floor and automatic sliding doors giving much easier access and enable the wheelchairbound to travel in the coach with other passengers.

Disabled Persons Railcard

Complementing all these initiatives and recognising the particular needs of permanently and severely handicapped people, BR in 1981 introduced its Disabled Persons Railcard — currently held by some 16,000 people. It costs £12 and allows the holder a year's rail travel at half the full fare or Awayday fare. The same reduced rate travel is available for an adult companion.

Future

As a next step, BR will be looking at ways of improving the door-to-door transport facilities for the disabled. The aim will be to simplify the journey through co-operation with other transport systems by providing clear information and ensuring that interchange facilities are available. This will embrace other public transport, recognition of the role of the car and taxi, and linking up with specialist transport operators for the disabled such as Dial-a-Ride.

BRITISH RAIL INFORMATION SERVICES

. . . New ASBAH Booklet . . .

MAKING OUR WAY

Individual experiences of young people with spina bifida and hydrocephalus

AS ASBAH comes of age in this its 18th year, it seems appropriate instead of looking back to look instead at some of those people with spina bifida and hydrocephalus who have grown up and come to grips with life in the last 18 years.

Their stories show some of the problems and challenges that these people have encountered and how they may have met them in different ways.

Making Our Way — forging some kind of enjoyable life despite disability — is the goal of hundreds of young people with spina bifida and hydrocephalus in this country. Many of them may not ask for or need ASBAH's help, but for those who do need assistance, whether in the form of advice or practical help and guidance, ASBAH will be there in the years ahead to make the way just a little bit easier.

SUSAN GEARING, EDITOR March 1984.

This is the Introduction to ASBAH's new booklet 'Making Our Way', published on March 15 this year. It is another of the 'circle in the cover' series, followed on from 'Little Joe' and 'Life and Death'. ASBAH is particularly pleased that Claire Rayner kindly agreed to write the Foreword to the booklet.

Price: £1 plus postage from ASBAH National Office.

JOHN GROOMS HOLIDAYS

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

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

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

Holiday Chalet: Near Skegness (Lincs) London Holiday Flat: London, N.4.

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

Bungalow: In the heart of the Norfolk Broads **Canal Holiday:** In adapted narrow boat.

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

Advertisement

HOLIDAY INSURANCE. particularly suitable for LINK readers. Only excludes travelling against medical advice. Details: Mr J. H. Fairhead, 29 Tunstead Road, Hoveton, Norwich NR12 8OG.

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Extra power to tackle the kerbs other chairs can only hope to, and a uniquely designed kerb roller to take you down front first.

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The most advanced Dudley heavy duty power wheel and transmission system, linked to a new control panel to give you an easier drive and greater manoeuvrability.

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A chair that's at home both outside and in, with the responsive power to cope with the countryside as well as the city. Its rugged yet portable frame folds compactly away in minutes to fit in the boot of a car unlike most of its competitors.

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... and then my parachute didn't open — until . . .

AS READERS of LINK will know, there are no lengths to which members of the Appeals Department will not go in order to secure the much-needed funds to support ASBAH's work.

Five of the staff, including myself, have even been so rash as to jump out of an airplane, complete with parachute I hasten to add, and we can, therefore, sympathise with the trials and tribulations of Russell Cory who also, as a member of the public, helped us by means of a sponsored jump. His report of the event makes interesting reading:—

"Dear ASBAH,

Most awfully sorry about the delay in returning my sponsorship money. But is seems that everything in connection with the parachute jump seemed to have been surrounded by near insurmountable difficulties. "All my arrangements for the

"All my arrangements for the weekend went awry. Firstly, I overslept and missed by first train. Then the second train went the long way via Ascot and Camberley. Thus I arrived late for the proceedings on Saturday morning.

"On Sunday morning my taxi didn't turn up for me and I couldn't get back inside to telephone them. And then, of course, we didn't get to jump on Sunday. It was another three weeks before I finally jumped and even that was plagued by delays and disasters.

"Firstly, the Red Devils airplane was in the Isle of Wight for some reason and so the morning, the best part of the day, was wasted. Secondly, once we finally got up I thought we might not jump as the wind strength and direction indicators dropped rather erratically. And even when I jumped my troubles weren't over. My parachute didn't open until I'd plummeted a good 500 ft. The cords got themselves tangled and although I managed to untangle



Going for the high jump . . . Colette Smith (secretary to Judy Kay), looking cool, calm and collected before her parachute jump.

them it gave my mother a few heart-stopping moments.

"It was most surprising I didn't do myself an injury on landing because the 'ground rush' totally deceived me. One moment I was airbourne and the next I was a squashed heap on the ground. "As you can imagine, there were the normal delays of collecting the sponsorship money, hence the

"Anyhow, enough of myself. I must thank you for giving me the opportunity to do the jump.

After the initial hassle it was very

delay in sending the cheque.

enjoyable.''

I think that Russell's letter does prove that fundraising for ASBAH is full of thrills and spills, but basically can be great fun. So, if any LINK readers feel like attempting any deeds of daring-do, why don't you give us a call on 01-388 1382 or drop us a line. We would love to hear from you.

JUDY KAY
Appeals Director

Local Association Secretaries

The following changes have taken place since the full Directory was published in the last LINK. (A full list will appear in the next issue):

Greenwich

Miss M Stredwick, Tower View, 17 Rusheymead, Brockley, London SE4 Tel: 01-690 3086.

Hillingdon Association (a new association)

Mrs Lorraine Christie, 8 Lonsdale Close, Uxbridge, Middx UB8 3BY.

NASBAH

This association has changed its name to ASBAH — Surrey.

South London

Mrs S Cudd, 15 Woodvale Walk, Elder Road, W Norwood, London SE27. Tel: 01-761 2400.

Wigan, Leigh & District Mrs L C Gill, 12 Greencield Road, Atherton, Manchester M29 9LW.

Worcestershire

Mrs Ann Cotter, 37 Leigh Grove, Droitwich, Worcs WR9 9LD. Tel: 0905 778925.

Llanelli & District

Tel. number (correction) Mr Phillip Williams' no. is: 0792 884465.

REMEMBER BABY . . . REMEMBER ASBAH

AN ASBAH Baby Book makes an attractive souvenir of a baby's first days, with spaces for baby's first photograph, baby's hand and footprint and details of the first holiday.

What's more, if you give the birthdate of the baby you will receive a free horoscope for his or her Star Sign. The horoscopes also include recommendations on how to deal with various quirks of character.

And remember every book sold helps ASBAH. The price is very reasonable — £1 each, including postage, from ASBAH National Office which is now at 22 Woburn Place, London WC1H OEP.

Classiff of

CLASSIFIED 'ADS'

The advertisement rate is: £2.25 for up to 30 words. £3.30 for 30-45 words. £4.50 for 45-60 words.

Please send remittance with your advert. Please note that there is a 10% discount if you book six advertisements in advance.

Adverts for the next LINK (May/June) should be in by April 5. Send to the Editor Mrs. Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

BARNSTAPLE, Devon. Luxury 7 berth purpose built holiday home. Excellent site. Ideal touring area, near beaches and beautiful scenery. £70 per week. Shropshire ASBAH. Bookings: Mrs S. Richards, Shrewsbury 59539.

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

BURTON BRADSTOCK. 6 Berth caravan, fully equipped. Pleasant site. Details: Mrs Bugden, 27 The Grove, Sholing, Southampton. Tel: Southampton 444921

CAISTER ON SEA. Two 6 berth caravans. Mains electricity, gas, shower, TV. Details: Mr L. J. Fletcher, 48 Humes Avenue, Hanwell, London W7 2LP. Tel: 01-579 2623.

CENARTH, W. Wales. Luxury chalet adapted for wheelchair. Sleeps 6. Colour TV. Heated pool, restaurant, shop, launderette. Details: Mr T. Noon, 14 The Chase, Leicester LE3 2WA. Tel: 0533 895691.

CLACTON ON SEA. 6-berth chalet at Highlands Chalet Park with outdoor pool, shop and clubhouse. Electric cooker, fridge, TV, shower. 5 mins. walk village with supermarket, shops and banks. Details: Mrs Bashford, Tel: 01-735 5489.

COLWYN BAY AND PWLLHELI. Two purposedisigned and built luxury 6-berth holiday homes with ramps, sited in Colwyn Bay and Pwllheli areas. Details: Mrs C. Hughes, 66 Sea Rd., Abergele, Clwyd, N. Wales. Tel: Abergele 824673.

GREATSTONE, Kent. 3 bedroom bungalow. Lounge, kitchen, well equipped large bathroom with hoist. Large garden. Close to safe, sandy beach and shops (200 yds). NE London association (NELASBAH). Details: Pierson, 18 Kingsley Road, E7 9PP. (S.a.e. please).

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

PRIMROSE VALLEY. Fully adapted luxury caravan. Sleeps 6. Bath/shower, ramp. Many facilities on site. Details: Mr J. Adams, 105 Blakey Close, Redcar, Cleveland. Tel: Middlesbrough 472920.

SELSEY. Luxury 6-berth purpose-built mobile home. Excellent club site amenities — pool, etc. Details: Mrs Budgen, 27 The Grove, Sholing, Southampton. Tel: Southampton 444921.

SELSEY, Sussex. Well equipped mobile home with 3 bedrooms and bathroom. (6 beds plus cot). Excellent amenities and entertainments. Details: Miss S. Newman, 2 Ashfold Avenue, Worthing, West Sussex, BN14 0AP. Tel: Worthing 64523.

SOLWAY FIRTH. 8 berth caravan, shower, toilet. Convenient for Scotland and Lake District. Details: Mrs M. Robinson. Tel: 0229 32657.

WESTWARD HO!, North Devon. Holiday Bungalow, sleeps six. Excellent Club, swimming pool. Shop on site. Near Sandy beach. Details: Mr G. Oakley, 12 Farleigh Road, Perton, Wolverhampton. Tel: 751484. (S.a.e. please).

WINTERTON ON SEA, Nr. Gt. Yarmouth. Fully equipped chalet. Sleeps 6. Indoor heated pool, shop, amusements, snacks, club, play areas. Details: Mrs A. May, 20 Ridley Close, Blaby, Leicester.

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

ASBAH booklets, etc . . .

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Your Child with Spina Bifida, by J. Lorber, MD, FRCP
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP35p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH
The Handwriting of Spina Bifida Children,
by Joan Cambridge and Elizabeth M. Anderson £1 Sex for young people with spina bifida or
cerebral palsy£1.25 The Nursery Years
by Simon Haskell & Margaret Paull
<i>Life & Death—thoughts on bereavement</i> 75p
Information leaflets
young people with spina bifida & hydrocephalus £1
Scottish Spina Bifida Association Booklets
The Spina Bifida Baby by O. R. Nettles, McSP, ONC . 40p
Growing up with Spina Bifida by O. R. Nettles, McSP, ONC
Keeping Fit by Jean M. Temple MCSP 10p
Self Help with Spina Bifida
by E. Wilson and E. Taylor
Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW.

EXCHANGE & MART

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

ON SAFARI



Saturday, 16th June 1984

A great day out — at special concessionary rates — for members of ASBAH, your families and friends, which will also help to raise funds for ASBAH.

 Drive through 7 Game Reserves (using your own coach or minibus)

Seaworld Show including Dolphins/Killer Whale Show & High Dive Spectacular

- Fun Run/Wheelchair Push with Prizes
- Safari Park Quiz with Prizes
- Extensive Areas for Picnics
- Children's Farmyard and Play Area
- Parrot Show



Planned in conjunction with asbah

To make your booking please complete this form and send it with full remittance to:

The Party Booking Office, Windsor Safari Park, Winkfield Road, Windsor, Berks SL4 4AY

Name of Group.....

Address.....

Est. Time of Arrival

Group Leader ...

Number in Party.....

No. of Wheelchairs

Total amount of cheque/PO enclosed (prices inclusive of

(Payable to Windsor Safari

Park)
No refunds will be given

The Park will be open from 10.00 am until 6.30 pm and the special 'fun day' price will be £2.00 per head (adult or child).



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The Supakart is a rugged, stable, outdoor vehicle which has a range of six miles, will mount shallow kerbs and climb steep gradients.

To have one, is to have fun, and you will see more places and people.

For further details contact: SPEEDWELL ENTERPRISES, NORTHAMPTON AVENUE, SLOUGH, BERKS. Telephone: SLOUGH 72249