Link

APRIL 1992 NO 139
Price 30 pence

The magazine for people with Spina Bifida and/or Hydrocephalus

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The Chiari factor explained

Call for national shunt register

ASBAH takes action over advertisement

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

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We care more

DAY CONFERENCE

organised by Westminster Children's Hospital School

'Spina bifida and hydrocephalus - provision for adolescents and young adults'

Wednesday, 6 May 1992

Venue: Board room, Westminster Children's Hospital

9am - 4pm

Main speakers will be Mr Nicholas Madden, Consultant Paediatric Surgeon, and staff from ASBAH.

Choice of workshops:

- Sexuality OR Continence
- Disabilty Awareness OR Independent Living

Details from Pat Aggarwal,
Westminster Children's
Hospital School,
Vincent Square, London
SW1P 2NS (Tel 081-746 8672)

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A PRESS advertisement for a mail order book which luridly described people with severe disabilities as "freaks of nature" has been condemned by ASBAH.

And a national newspaper group, which carried the advert earlier this year, has told an ASBAH member that it will never do so again.

"I agree that this advertisement is vulgar, insensitive and likely to cause hurt," Mirror Group Newspapers advert director Mark Pritchett told Miss Annette Hull, of London, who had complained. He apologised "unreservedly" for any distress caused.

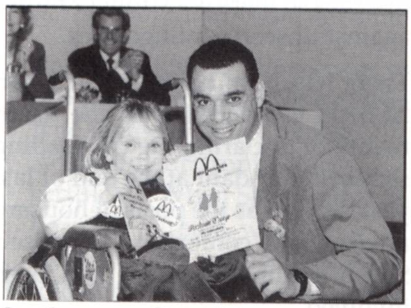
ASBAH executive director Andrew Russell wrote to the Advertising Standards Authority asking for the advert for a book called 'Medical Curiosities' to be banned after it was spotted in The Sun newspaper. The advert carried a picture of a man said to have hydrocephalus.

"The advertisement - linking the condition of hydrocephalus to a grotesque litany of human phenomena such as 'hideous cannibal rites', 'sexual anomalies', the 'rare and bizarre' - not only stigmatises the people we exist to help but will, I believe, deeply offend many of them," Mr Russell told the ASA.

"Hydrocephalus is a disability which, like many others, needs to be understood - with society making adjustments so that individuals are given every chance to fulfil their potential, and live as independently as possible. This advertisement (and the nasty little book it promotes) makes that process of building bridges no easier to achieve."

The ASA at first declined to act, saying the advert did no more than represent the contents of the book, and did not contravene their Code of Practice. They had to weigh the balance of the "undoubted liberty of the advertiser to free expression" against the need of the "unoffended majority to hear what the advertiser wishes to say".

After Mr Russell wrote again to the ASA, the authority - in a second letter sent to ASBAH in March - wrote back: "In view of the quantity and status of complaints received since our original adjudication, we have asked the advertisers to re-consider their advertising approach. Since the advertisers are breaking no law, we cannot prevent them from advertising this product, but we can request that it be done in a manner which is responsible and causes minimum offence".



On the cover: Steve Johnson from TV's Motormouth presents Stephanie with her Child of Achievement Award. See page 5.

The ASA told ASBAH's executive director that the company involved wanted to advertise the book again and wished to discuss the matter directly with ourselves to obtain our views on appropriate amendments.

"I'm considering that suggestion. But I do not want to place ASBAH in a position where we could be seen to be giving the book our seal of approval," Mr Russell told LINK.

The magazine for people with spina bifida and/or hydrocephalus
Editor: Gill Winfield
Published by **ASBAH**,
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Peterborough PE1 2UQ
Telephone: 0733 555988.

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UK	£3.30
Europe and Overseas Surface Mail	£5.60
Air Mail	£12.50

All payments should be made in Sterling.

Registered charity no. 249338.

Sunny outlook for Fund-a-Fieldworker Campaign

In Leicestershire the Fund-a-Fieldworker Campaign has received a £500 boost as a share of last year's fundraising efforts by RAF Cottesmore. The Base, which hosts officers from other NATO flying services as well as the RAF, has pledged to give even greater support for Fund-a Fieldworker from their fundraising this year.


Paul Wootton,right, receives the cheque from officers at the base.

And Kelloggs, producers of that well known 'sunshine breakfast' are bringing a ray of sunshine to ASBAH's fieldwork service in the Manchester area - they have pledged £8,000 to our fund-a fieldworker campaign.

Greater Manchester became the obvious choice for the next stage of our Fund-a-Fieldworker Campaign when a legacy provided ASBAH with a substantial donation to be spent in this part of the country. Now Kelloggs have become the first company to contribute to the Campaign in Greater Manchester, with a Deed of Covenant for the next four years, donating £2,000 each year.

Information for drivers

Two new information sheets are available from the Joint Committee on Mobility for Disabled People, on which ASBAH is represented.

Sheet number 1-92 covers the regulations on Illegal Display of the Orange Badge, sheet number 2-92 explains the Road Traffic Act 1991.

Both information sheets are available free from RADAR, Publications Department, 25 Mortimer Street, London W1N 8AB. Please enclose a 22 x 11 cm stamped and addressed envelope when sending for the leaflets.

Folic Acid leaflet

ASBAH has produced a leaflet on Vitamin Supplementation in the Prevention of Neural Tube Defects, to add to its series of information sheets - available from National Office. This sheet (Information Sheet 5) gives the background and latest information on the importance of folic acid in reducing the risk of neural tube defects - spina bifida, anencephaly and encephalocele.

ASBAH has asked the Department of Health to tell us how they propose to make folic acid more readily available to women, in the dosage required, as an effective preventative measure.

PROSPECTS IMPROVE FOR ASBAH

Cautious optimism that ASBAH is well-placed to take advantage of an increase in charity-giving once the recession ended was expressed by the directors at ASBAH's six-monthly Council meeting held in Peterborough last month.

"We hope our budgets will prove to be over-pessimistic and that, during the next year, things will improve and that we shall be able to restore some of our service provision," said finance director Derek Knightbridge.

ASBAH is likely to finish this financial year £110,000 in deficit with reserves of £350,000 (equal to just three months salaries, National Insurance contributions and expenses). The actual deficit will compare with a budgeted figure of £142,000.

Mr Knightbridge forecast that the deficit will be reduced to just £10,000 at the end of 1992/93. Attempts would have to be made to build up reserves so there is a stronger buffer against unseen contingencies.

There had been no fat to cut when ASBAH was faced with the harsh reality of declaring the counselling service redundant at the end of last year, as well as the posts of housing adviser and conference organiser. Seven members of staff had been involved.

"These cuts have damaged our services. I don't claim to pretend otherwise", said executive director Andrew Russell. But he remained "reasonably confident" that some of that damage to services will be repaired in the next year.

Council heard how immense efforts are being made, in extremely difficult economic conditions, to increase income from telesales, trusts, companies, Government, local authorities and the public.

Guest speaker was Malcolm Ashman, Lincolnshire's director of social services, with formal contributions in the afternoon from Mrs Pauline Wood, chairman of North Wales ASBAH, and Mrs Margaret White, organising secretary of Sussex ASBAH.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Senior Staff

Executive Director:
Mr Andrew Russell, MA

Finance Director:
Mr Derek Knightbridge, FCCA

Assistant Director (Personnel)
Mr Paul Dobson, BA (Hons), MIPM

Fieldwork Manager:
Mrs Teresa Cole, MICA

Disabled Living Service Manager:
Miss Rachel Stanworth, BA (Hons), SRN, PGCE, MSc

Publicity Manager:
Mr Tony Britton

Research and Information Officer:
Miss Pat Corns, SRN

Five Oaks Centre Manager:
Miss Joan Pheasant, NNC

Appeals Manager:
Mr Roy Johnston

Business Liaison Manager:
Mr Paul Wootton

Loadsa money from ASBAH's TV appeal!

£57,000 has flooded into National Office in direct donations and as a result of introductions after ASBAH's first TV appeal for almost eight years, in February.

Appeal line: coach driver Steve Marshall and some of the volunteers who staffed the telephones.

A cheerful, though nervous, band of volunteers took the coach trip to London on that Sunday afternoon to answer the phones when the programme finished: "As soon as the number came up on the screen the phones went mad," said fieldwork secretary Kate Stilwell. And that night they took £5,634.50p in credit card donations. The donation collection service, which at the time said it was the best appeal they had run for some months, told ASBAH we could expect to treble that figure in the following week, from postal donations. So we're even more delighted to have achieved a ten-fold increase on the initial total.

Our thanks go to all those involved: Ruth Madoc and the McKernan family - who appeared in the film, ITV network appeals producer Gerry Dawson and his team at Harlech TV West; Stamford coach firm Fairtax and driver Steve Marshall who took the volunteers to London.

Our children of achievement

ASBAH was well represented in this year's Child of Achievement awards which were presented at the Queen Elizabeth II Conference Centre in February.

Children with spina bifida and/or hydrocephalus from as far afield as Northern Ireland, Sussex, Wales and Devon were some of those honoured.

It was a great day out for the chidren who had a chance to meet some of their favourite TV personalities - Andy Crane, Timmy Mallet and Steve Johnson were among those presenting the awards, as well as Prime Minister John Major.

There are thousands of nominations for the awards from which 150 are selected. Some of those chosen were children with disabilities who have faced many hospital admissions for operations or infections and come out smiling.

Young Stephanie Thorpe was one of a number of ASBAH children who were given a 'Child of Achievement' trophy and certificate. When Stephanie was born her parents, who are members of Kent ASBAH, were told she wouldn't survive but after many setbacks five-year-old Stephanie was finally given a clean bill of health last year.

Ruth McClure flew over from Northern Ireland to receive her award and managed to squeeze in a trip to the theatre to see Philip Schofield in Joseph and the Amazing Technicolor Dreamcoat. Fourteen-year-old Ruth was nominated by the headmaster of the local mainstream school she attends - in a glowing nomination he listed her many activities from drama to being a leader in the boys brigade, she was described as willing to have a go at anything and always smiling.

Congratulations to Ruth, Stephanie and all the 'children of achievement'.

A voice for children with special educational needs

Two national bodies have combined to provide a more powerful voice for children and young people with special educational needs. Formed by amalgamating the National Association For Remedial Education and the National Council for Special Education; NASEN (the National Association for Special Educational Needs) is now the largest organisation of its kind in the UK.

ASBAH is a member of NASEN but individual parents can join one of NASEN's local branches at an annual rate of £15. This entitles you to a broadsheet, access to specialist advice and branch support. Teachers and professionals with an interest in special educational needs also receive a quarterly journal - their membership rate is £20.

For application forms, write to:
NASEN
Membership Dept
York House
Exhall Grange
Wheelwright Lane
Coventry CV7 9HP
Tel: 0203 362414 (24 Hours)

Support for Parents

There are several organisations offering support and contacts for parents of children with special needs. Two of these are Contact a Family, which runs a national network of support groups, and In Touch, which links individual families with children with specific disabilities.

Their addresses are:

Contact a Family
16 Strutton Ground
London SW1P 2HP
Tel: 071 222 2695

In Touch
10 Norman Road
Sale
Cheshire N33 3DF
Tel: 061 905 2440

And for parents with disabilities, a group based in Derby run an informal helpline so you can chat to a disabled parent about any worries or problems you might be experiencing. Telephone Able Parents Together on 0332 770833 - daytime only.

On the move

The British Council of Disabled People (BCODP) has changed its address to:

De Bradiliei House, Chapel Street
Belper, Derbyshire
Tel: 0773 828182

Name Change

The Northern Ireland Council on Disability has changed its name to Disability Action.

National survey of maternity care for disabled parents

If you have been pregnant in the last five years and have a physical disability which affected your daily life at any stage during pregnancy, birth or the first six months, then the Maternity Alliance (MA) would like to hear from you.

They are conducting a survey to find out what the experiences, needs and wishes of pregnant women and parents with disabilities have been. From the results of the research they hope to produce a report with recommendations for the development of policies and practices which meet the demands of pregnant women with disabilities.

The survey has been devised by MA's Disability Working Group, which is made up of parents with disabilities and representatives from over 30 organisations (including ASBAH) in the disability and maternity fields.

If you would like to complete a questionnaire (all information will be treated in the strictest confidence) contact The Maternity Alliance, 15 Britannia Street, London WC1X 9JP, telephone 071 337 1265.

French Exchanges

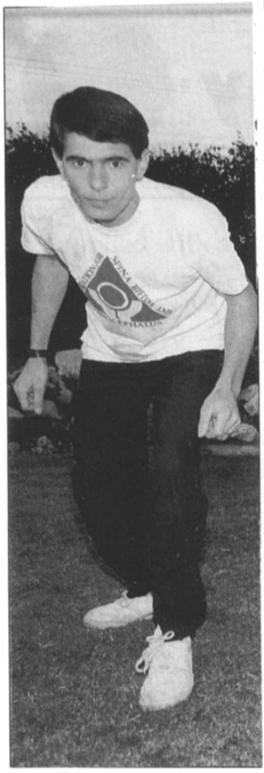
Jerome is a 16-year-old boy with spina bifida who would like to come to England to stay with a family who have a teenager with the same disability.

Jerome has a shunt and wears orthopaedic shoes but is very "self sufficient". He has been learning English for two years. His family would be happy to accommodate an English boy for next year's holiday, in exchange.

If you can help, contact Monsieur & Madame Dejaegere, 6 rue Camille Desmoulins, 59282 Douchy-Les-Mines, France.

Cedric Courtinel has spina bifida and hydrocephalus and enjoys the outdoors (canoe, kayak and sit ski) and his English classes. He is looking for someone of a similar age and situation to visit in England this summer, and to visit him in France in the future.

Contact: Sheila Ott, Handicap International, 14 avenue Berthelot, 69007 Lyon France. Tel: 33.50.67.47



The best laid plans. . .

Kevin Daily, a Cambridgeshire resident whose daughter Joanne has spina bifida and hydrocephalus, had persuaded two friends to run for ASBAH with him in the London Marathon this month.

One, Tony White, had to drop out because of an ankle injury and then the other, local landowner Tom Mott, developed Achilles tendon trouble.

"There I was, two catastrophes in a row, but determined not to be beaten", said the ever resourceful Kevin, who lives at Little Downham, near Ely.

He persuaded two fit runners to join him instead - neighbours Jeremy Swan and Nicola Hector.

LINK offers consolation to those who had to drop by the wayside with our hopes for speedy recovery, and the best of luck to all ASBAH runners taking part in the big event on 12 April.

We hope to bring you reports of how they got on in our next issue.

Caravan appeal

Bucks and East Berks ASBAH got their appeal for a new holiday facility off to a good start when they launched it in the autumn last year. They now have £3,000 of their £15,000 target.

The Association already has a chalet at Winterton-on-Sea, some five miles from Great Yarmouth on the east coast, which they often advertise in LINK's holiday accommodation section. But as their treasurer, Mr Fred Simmons, told LINK: "It was fully booked last year and we had to turn some people away, so we decided to do something about it".

The committee is now hoping to provide a fully adapted caravan in Weymouth, for use by young people with spina bifida and/or hydrocephalus, with the emphasis on independent holidays.

Future fundraising events for the caravan include a 60s night and teddy bears picnic but they would be happy to hear of any fundraising ideas from other local associations - contact Mr Simmons on 0628 783413 if you have any suggestions.

Help at hand for learner drivers

A register of driving instructors providing tuition for disabled people, held by the National Mobility Centre in Shrewsbury, is just part of their Driveable scheme - set up to put disabled people in touch with specialist instructors.

The scheme also includes a newsletter for approved driving instructors, on matters relating to disability and roadcraft, and provides support for new instructors wishing to gain experience in the field. Many of the instructors in the scheme have their own adapted vehicles and each has access to a data bank, advice line and driver assessment facilities at the National Mobility Centre.

For details of your nearest Driveable instructor contact Jean Griffiths, Administrator, National Mobility Centre, Unit 2a Atcham Estate, Shrewsbury SY4 4UG. Telephone: 0743 761889.

The voice of our disabled members - a discussion day

National ASBAH is planning a discussion day at our Peterborough headquarters to find out where our disabled members feel our services are succeeding and what else they would like us to do.

The meeting is free and lunch, tea and refreshments will be provided. It is open to any disabled member but as space is limited, bookings will be accepted on a first-come, first-served basis.

After small group sessions in the morning, there will be a chance to join in discussions with the whole group with ASBAH's chairman Patrick Daunt and other Executive Committee members, as well as members of National staff.

A report from the meeting will be considered by ASBAH's full Executive Committee.

The discussion day will be on Wednesday 27 May at ASBAH House, 42 Park Road, Peterborough, from 10.30am - 3.30pm. The venue is fully accessible.

The discussion day is open to all ages. To book your place please contact Tony Britton at National Office, telephone 0733-555988.

The Chiari Deformity

The most important secondary effect of spina bifida is deformity of the lowest parts of the brain and the top of the spinal cord. Commonly called the Chiari deformity, this abnormality can also be found with hydrocephalus or with syringomyelia, or with any combination of these disease processes or without any of them.

Mr Bernard Williams MD, ChM, FRCS, who works for the Midland Centre for Neurosurgery and Neurology and is also a member of ASBAH'S medical advisory commitee explains the various forms of Chiari malformations or hindbrain herniations.

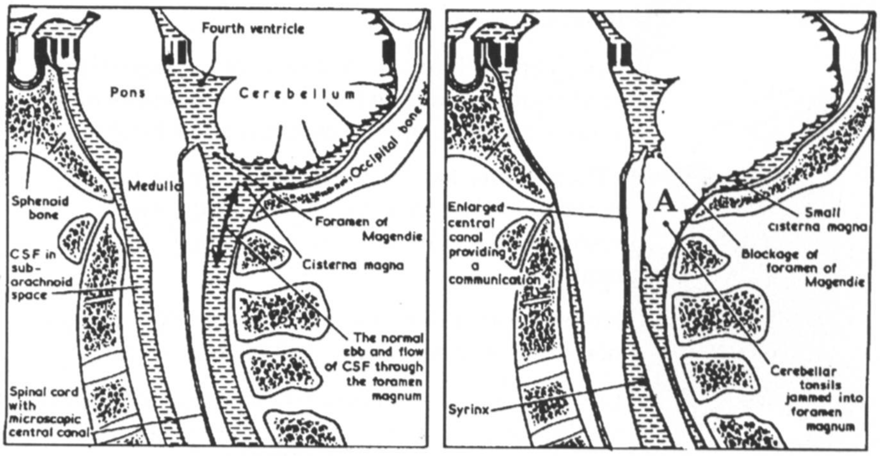


Fig 1: Midline section through an unaffected case on the left. Hindbrain hernia ***(A)*** *and syringomyelia on the right.*

The characteristic features are shown in Fig 1. In the normal the fourth ventricle opens through a midline outlet channel into a space called the cisterna magna.

The first two types that Chiari described are the commonest and they are sometimes referred to as Chiari type I and Chiari type II. It can be seen from the illustration that they are both likely to be due to downward pressure acting on the base of the brain and the spinal cord so that the brain tissues appear to be trying to flow out of the head into the spine. They are thus due to a similar pressure deformation and they are both characterised by the same features, that is the brain has been forced down through the foramen magnum, the large hole at the base of the skull, into the upper part of the spine.

The clear division between type I and type II is not always present. Some of the Chiari type Is have medullary deformity, widening of the foramen magnum, smallness of the posterior fossa and associated hydrocephalus for instance, but the extent of the deformity is so mild as to still make them closer to type I than to type II. Likewise type II patients may have a modest or a severe deformity. In the worst, the whole of the cerebellum has migrated into the spinal canal. Such deformities are not compatible with life. I refer to all these deformities as hindbrain herniations and divide them according to the causes and the time of presentation.

Congenital disorders

Medical students are sometimes taught to divide disease processes into such groups as infective, malignant, degenerative, and toxic. They include the heading "congential" commonly. Congenital, however, is not a disease process. Congenital is a time of life, it is a useful phrase because it means acquired in mother's womb or present at birth. What we used to call congenital diseases were often genetic disorders. Plainly if there is something so wrong that the genes are defective, for example haemophilia or Down's Syndrome, then the abnormalities are congenital. Other problems in the foetus, however, are toxic, some are infective, some are due to deficiency states and others are due to mechanical influences such as intrauterine adhesions which in an adult would be classified along with accidental or traumatic cases. To call hindbrain herniations congenital, therefore, does nothing to explain them.

The age of onset of the problems that cause hindbrain herniation is important. If the hindbrain herniation comes on in the early stages of foetal development then it is likely to be more severe than if it comes on in adult life. This is the basis for the difference between Chiari type I and Chiari type II.

The Chiari type II malformations are more severe because the downward force occurred when the developing parts of the central nervous system were plastic and responsive to pressure difference (Fig 2). There are two main causes of pressure differences across the foramen magnum, abnormally high pressure within the head and low pressure inside the spine. The severe early onset abnormality known as Chiari type II is due to low pressure in the spine.

Shortly after conception the foetus is a tight ball of cells and it consists of little more than a massive heart with the brain and spinal cord wrapped around the back of it.

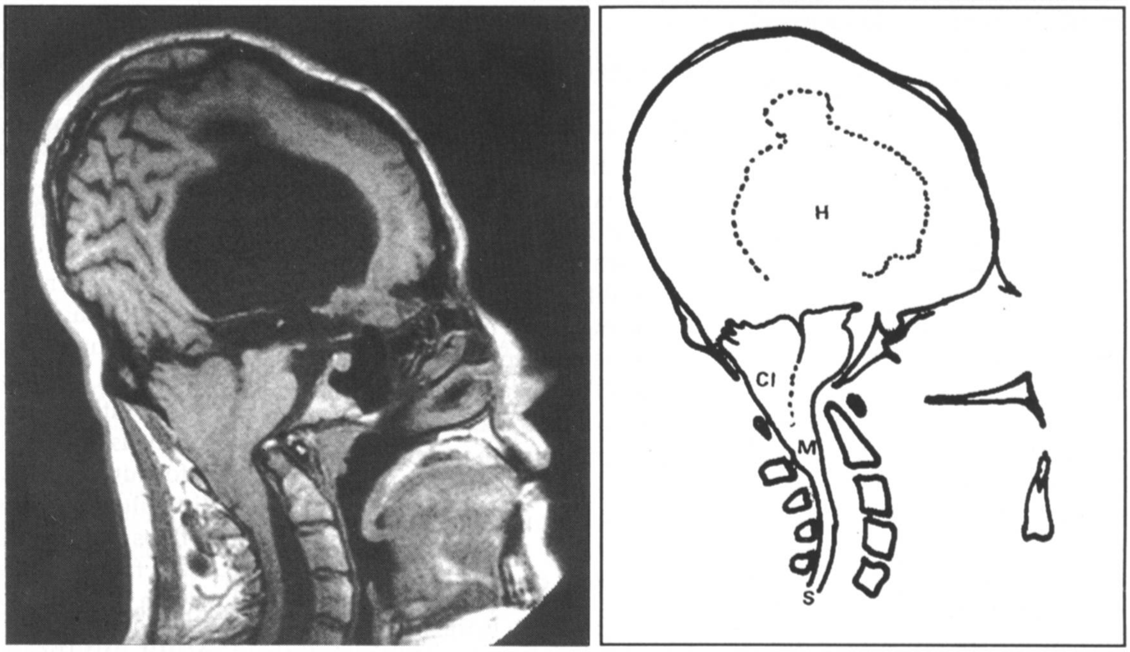


Figure 2: Infantile hindbrain herniation (Chiari type II) as seen on MRI scan. Note that there is hydrocephalus (H), all of the hindbrain is pushed downwards through the foramen magnum by the hydrocephalus. The cerebellum (CI) and medulla (M) are blended together and there is no fourth ventricle visible. This patient has reached adult life without treatment. A hydrocephalus shunt was successful.

The whole thing throbs under a pressure which is enormous relative to its size. The brain and developing cord are supplied with a rich mass of blood vessels which carry nutrition to produce the enormous complexity of the human organism which is built within a remarkably short time. The reason why we spend nine months in our mother's uterus is to get big enough to live, not to have the framework of the organs laid down.

The central nervous system is formed by the development of a groove on the back of the foetus. This groove deepens and the lips meet in the midline. The fusion of the two sides of the groove then spreads up and down until all the central nervous system, the brain, spinal cord and nerve root ganglia are buried safely under the skin. Bone then forms around the nervous system and keeps it in and protects it, so that the pressure within the skull and spine is slightly higher than that outside the foetus.

If there is a spina bifida, due to the failure of the back of the spinal cord to close during the third week after conception, then the skin and the membranes or, in extreme cases, the spinal cord itself becomes blown out by the overall pressure within the embryo. This contributes to the deformity of the back and because it induces a low pressure state inside the spine the brain moves down through the foramen magnum in response to the pressure differences. The major part of this deformation occurs before the fourth week after conception.

What harm does it do?

In the Chiari type II malformation the descent of the outlets of the cerebellum into the foramen magnum obstructs the outlets of the cerebrospinal fluid from the ventricles. Thus the hydrocephalus is caused by the hindbrain herniation. Hydrocephalus in its turn produces other deformities inside the head and because of the great size of the parts of the brain above the tentorium that pushes the tentorium downwards and contributes to the hindbrain herniation. This is, therefore, a typical disease process which aggravates it own progression.

By the time children with spina bifida are born the hydrocephalus cannot be successfully treated by operating on the hindbrain hernia. Hydrocephalus requires treatment of itself. Some babies have symptoms from the hindbrain herniation. Sometimes it seems to be associated with breathing difficulties or controlling the vocal cords; it can be marked by swallowing problems and eye movement difficulties. It is difficult to test the lower cranial nerve functions in a baby but, by analogy with adults, it can be assumed that other lower cranial nerve functions are affected. There is disagreement about how frequent this is. Operation on the hindbrain herniation may be helpful.

In adults the harm a hindbrain herniation causes is variable and complex. It acts as a valve and in this way it allows fluid from the spine to enter the head more easily than it allows it to flow the other way. It might be wondered what effect that has; it is not immediately obvious. The effect of raising the pressure in the abdomen and in the chest is to distend the veins around the epidural canal and this forces CSF into the head by compressing the dural sac. In the normal, of course, it ebbs and flows through the foramen magnum and without impedance (Fig 1). When there is a valvular action there, and the

Continued on Page 10

hindbrain hernia makes a closely fitting valve, the pressure builds up in the head higher than it does in the spine and this moulds the hindbrain more firmly into the foramen magnum. Thus there is again another system in which the disease process aggravates its own progression.

When the spinal cord is compressed at the top in this way many results can ensue. The first is the compression of the spinal cord and the tracts within it. This can produce involvement of motor power and also sensory function; that is to say feeling, from almost any part of the body, including a good deal of the face. Pressure can also be exerted on parts of the brain looking after the eye movement and balance. Symptoms such as dizziness and fainting can be a problem.

The next feature is that such impaction can be painful. It is known that it may occur without pain but for some, hindbrain impaction is acutely painful. It is worse after straining of the sort that has been described above as pushing CSF into the head. Thus pain may come on after standing up suddenly, bending down to pick something off the floor, shouting, coughing, sneezing, laughing or any sustained exertion. Characteristically the pain is pounding and intense, involving the base of the skull; sometimes the neck, occasionally the ears, often passing up to the top of the skull and often present on one side more than the other.

The next mechanism to consider is syringomyelia. This is the condition of longitudinal cavities occurring within the spinal cord (Fig 1). It is not a disease, it has many causes including spinal tumours and the various forms of disturbance of development such as spina bifida. The commonest cause in adults is a problem at the foramen magnum, this is called hindbrain related syringomyelia. The commonest of these is adult hindbrain herniation or Chiari type I deformity.

Syringomyelia causes destruction of the soft central parts of the cord, this means disturbance of sensation especially inability to feel temperature and pain. If the condition progresses it produces generalised numbness, lack of mobility and strength, with wasting of the upper limb muscles and usually spasticity of the legs. Sweating disturbance and unequal pupils may occur. Although slow it is commonly a progressive disease and, although it may arrest at any time, is sometimes relentlessly aggressive and may lead on to death if untreated.

Syringobulbia is the name applied to dysfunction of the lower cranial nerves. Usually there is no cavity causing such problems but sometimes there is an upward extension of a syringomyelia cavity from the cord or else downward splitting of the floor of the fourth ventricle, which may be described as fourth ventricular clefts.

The symptoms of syringobulbia can be severe and include features difficult to analyse such as giddiness, headache and double vision. Sometimes the eyes jerk in a rhythmic manner. The jerking is called nystagmus and the subjective sensation is oscillopsia, when objects appear to jump up and down. Other features such as deafness, tinnitus, tongue or palate paralysis, voice involvement and swallowing difficulty are due to nerve involvement.

What should we do about it?

Hindbrain hernia in infancy.

When this has produced hydrocephalus it is often necessary to shunt the hydrocephalus by a valved shunt either ventricle to peritoneum (belly) or ventricle to atrium (heart). It is not advisable to operate on the Chiari malformation for relief of hydrocephalus, the results are calamitous (Fig 2). The question of whether an operation should be done for such things as respiratory failure may involve ethical decisions. if operation is not done it might be seen as akin to euthanasia. Nevertheless, if the Chiari malformations are so bad that the child is having difficulty in breathing then the situation is almost certainly one where there is severe neurological deficit and the likelihood of a total, high spina bifida with the problems of paralysis, foot deformity, spine deformity, bowel and bladder difficulty, mental inadequacy, epilepsy and a strong likelihood of death from shunt complications within the first few years of life.

Adult hindbrain herniation

When this is causing pain, cranial nerve palsies, syringomyelia or syringobulbia, it should almost always be operated upon. Careful surgery can almost always produce correction of pain. Lower cranial nerve dysfunction oscillopsia, giddiness and gait problems are usually markedly helped and syringomyelia, although seldom completely cured, is often meaningfully improved and arrested.

Conclusion

The Chiari malformations are a variable group of conditions best described as hindbrain herniation. For purposes of discussion they are conveniently divided into those of infancy and childhood, Chiari type II and those of adults, Chiari type I. Some of the clinical problems and the place of surgery have been discussed.

Further Reading

"Malformations" In clinical Neurology, Edited by Swash and Oxbury, Churchill Livingstone.

"Pathogenesis" In Syringomyelia: Current concepts in diagnosis and treatment. Edited by Batzdorf, Saunders.

Does your child's school know about UDET?

Integrated education can have many benefits but occasionally we hear of a disabled child in mainstream school who has fallen victim to inappropriate attitudes from their able bodied classmates. This can range from jibes and avoidance to downright hostility. This behaviour can be the result of the able bodied children's natural fear of the unknown and their misunderstanding of disabilities. This is where UDET can help.

UDET, the Understanding Disabilities Educational Trust, was formed to combat this misunderstanding and replace it with sensitive awareness and understanding. They have developed an educational programme, aimed at primary and young secondary school children, which introduces the topics of physical, hearing, learning and visual impairment to the pupils during a school term. The programme is well thought out: "Using simple language and wall charts, it is explained how the relevant part of the body *does work* and why sometimes *it does not.* Children do exercises to help them imagine the effects of disability. Then by examining specially designed equipment, the children learn how this can be used to increase independence and mobility. The participation of disabled 'guests' is also a very important part of the programme."

The UDET package has been given glowing reports by the Times Educational Supplement: "The materials are simply excellent. The coverage of topics is comprehensive and accurate, the presentation is always clear and sometimes inspired". And the Daily Telegraph commented: "...an invaluable teaching aid. Starring a variety of disabled children and adults, the videos tackle the issues raised by visual, hearing, physical and learning disabilities in a remarkably frank and enlightening way".

You can obtain leaflets with more details of the work of UDET from Weydon School, Weydon Lane, Farnham, Surrey GU9 8UG, telephone: 0252 733167. So why not bring it to your school's attention.

More help on using computers

In the last issue of LINK, our education adviser, Peter Walker, looked at how useful computers can be as a learning aid for children with special needs. Since then another organisation to help disabled people get the best out of their computers has come into operation.

The Computability Centre will build on the British Computer Society's Disability Project and the Freephone service operated by IBM to provide a comprehensive information service for computer users with disabilities. The Centre will also provide education and training on the opportunities that computers offer, particularly with regard to employment aspects.

A consultancy service is to be offered by the Centre to assist in the selection and matching of computer equipment for people with disabilities, purchasing, technical advice on installation and use, and other physical requirements, both in the workplace and domestic situation.

The Centre will support individuals, professionals and others in the caring services as well as other professional organisations.

You can contact The Computability Centre at PO Box 94, Warwick, Warwickshire CV34 5WS, telephone 0926 311345.

Diary Dates

16 May: Special Children's Day at London Zoo. Talks, tours, arts/crafts for children with special needs. Tel: 071 722 3333 ext 551

21 May: Continence Management Study Day. For professionals, at Peterborough Central Library. Fee £30. Contact Lynn Thomas at ASBAH, 0733 555988.

9 June: Disabled Women Organise! - A day of celebration is the theme of this event for disabled women, which is being organised by the Greater London Association of Disabled People (GLAD). There will be discussion groups, information stalls, videos and entertainment throughout the day. A creche is available. Further information from Orla Fox or Donna Jackman-Wilson on 071 274 0107.

1 & 2 July: 75th Anniversary Conference, Exhibition and Open Day at Papworth Trust. The conference on 1 July will be chaired by Lady Masham and will focus on employment issues and examine the role and effects of new technologies.

The Papworth Trust owns most of the village of Papworth Everard and provides opportunities for disabled people to work there in an integrated workforce. On 2 July anyone is welcome to explore the village and see what services the Trust offers. The exhibition, on both days, will show products and services of interest to disabled people. More details on the conference and exhibition from: Effective Technology Marketing Ltd, Enterprise House, Wilton Road, Humberston, Lincs Tel: 0472 210707.

A case for audit of shunts for hydrocephalus

Professor J D Pickard, of the Neurosurgery Unit at Addenbrooke's Hospital in Cambridge, explains the need for a national register of CSF shunts.

"Insertion of a CSF shunt is the only satisfactory treatment for the majority of patients with hydrocephalus. The only exceptions are those premature infants with post-haemorrhagic hydrocephalus where drug treatment may tide them over until they open up their CSF pathways or are old enough to have a shunt inserted with less risk of complication (See LINK No 137 pp 13-15).

There has been considerable surgical ingenuity directed at how to divert cerebrospinal fluid so that it may be absorbed elsewhere in the body. The first modern valves were inserted in the 1950s (Nulsen and Spitz 1952). However, the perfect valve has yet to be devised, despite much effort on the part of neurosurgeons, engineers and industry. There is a large range of different types of valve (see table).

Statistics of shunt failure

A number of studies from around the world have now revealed that a substantial number of shunts require replacement over the years. Such failure originates from many factors, including problems with the shunt valve, ventricular catheter, peritoneal and atrial catheters, in addition to individual problems presented by the patients themselves.

Failure is more common in the first six months of life but there are particular groups of patients later in life at risk of problems with insertion of a shunt and patients may become very ill despite years of apparent stability. Patients presenting with hydrocephalus in childhood may require a number of shunts over their lifetime.

Table 1

	Type of Shunt	No of versions
1	Non programmable - fixed characteristic - proximal control	28
2	Programmable Shunts	2
3	Variable Shunts	2
4	Distal Control - Slit valve	6
5	Lumbo-peritoneal Shunts	8
6	Miscellaneous	3

Economics

Approximately 3,000 shunt operations are performed in the United Kingdom per year, of which 1500 are new and 1500 are revisions (Marchbanks 1989). A total cost in the United Kingdom of in-patient care for shunt operations per year is of the order of £6 million at 1983-84 prices based on the Wessex Neurosurgical Cost Benefit Study (Pickard 1990). However, if various factors reflecting quality of life are taken into account, the cost for such surgery compares very favourably with other areas of medicine. Not only is surgical intervention for hydrocephalus essential for the patient's survival and well-being, in 1992 it also makes economic sense.

Independent bench testing of shunt valves

National standards have existed for some years that must be met by manufacturers. British Standard BS6788 (1976) tries to ensure that valves behave on the bench in the way that the manufacturer intended. A number of studies have now shown considerable variability of individual valves from a particular range when tested in such shunt rigs. Briefly, a valve is placed in a water bath and fluid similar to cerebrospinal fluid is pumped through the valve at a rate comparable to what happens in a patient. Various pressures are measured over a period of days and weeks, again to mimic behaviour in a patient.

More sophisticated bench testing is now available than that required for BS6788 and such a rig is established in this Department. Despite the best efforts of manufacturers, some shunts removed new from their wrappers, when tested in such systems, have not behaved according to the manufacturer's own specifications. Much discussion is taking place to establish more rigorous standards of testing both with the manufacturers and independently that can be agreed internationally.

Analogy with artificial heart valves

Problems of failure of various heart valves were noted some years ago with unfortunate consequences. As a result the Department of Health has now established a number of mechanisms nationally to document failure of such artificial heart valves and also to evaluate valve function in a specially designed rig. Every heart valve inserted in patients is now centrally registered with the UK Heart Valve Registry based at the Hammersmith Hospital and long term studies of such heart valves are documented in the multi-centre valve study based in Sheffield. Artifical heart valves are rigorously evaluated in Sheffield in the IBEES Unit.

Proposal for audit of hydrocephalic shunts inserted in the United Kingdom

With the agreement of the Council of the Society of British Neurological Surgeons, the Executive Committee of the British Association of Paediatric Surgeons, the United Kingdom Shunt Discussion Group and ASBAH, discussions are taking place to establish two different types of audit. Firstly, a UK CSF shunt evaluation unit should be permanently established with the following aims:

★ To provide a formal evaluation for every type of CSF shunt system.

★ To provide individual feedback to neurosurgical units supplying shunts that have been removed from patients.

★ To make recommendations for guidelines to be adopted for test performance.

★ To collaborate with standards authorities both European and worldwide. Such a shunt evaluation unit has now been established in Cambridge.

The second audit mechanism would be provided by a UK CSF Shunt Registry based on the very successful UK Heart Valve Registry. Every shunt inserted into a patient in the United Kingdom will be centrally registered by a simple form and any revision would be similarly registered. Appropriate confidentiality will be preserved.

The type of shunt and individual product number would be recorded. With 3,000 shunt operations per annum in the United Kingdom, a large database would be established rapidly and failure of individual types of valves would be highlighted at an early stage. It would be very difficult for any one Neurosurgical Unit to insert enough valves over the period of a year to be sure of the importance of failure of a particular valve. Only by coming together and reporting all shunts in the United Kingdom can this type of problem be highlighted.

Conclusions

It is very important to stress that the great majority of patients with shunts inserted for hydrocephalus pursue very active and productive lives with very few complications, particularly with recent advances in brain imaging, shunt technology and surgical technique. However, there is no doubt that we need to audit every aspect of our care for our patients to try and reduce any complications still further."

References

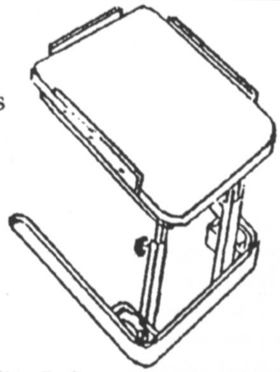
1 Nulsen FE, Spitz EB. Surgical Forum, American College of Surgeons Vol 2: 399 1952. Treatment of hydrocephalus by Direct Shunt from Ventricle to Jugular Vein.

2 Marchbanks RJ Z Kinderchir 1989. Vol 44, Supplement 1:13.

3 Pickard JD. BMJ 1990: Vol 1 629-635.

Product News

Chair/Bed Table



Designed and manufactured on the Isle of Wight, this fully adjustable table measures 23 by 18 inches and has a tweed weave top surface, coated in clear vinyl. Small ridges on three sides prevent books or paper from sliding off when the table is tilted. The table is sturdy enough to support the weight of the user and it can be personalised with your name or logo, free of charge. The cost is £59.90. For more details, contact Mr Ross Chisholm at SPX, Unit 3, Parkhurst Road, Newport, Isle of Wight. Tel: 0983 821778.

New Disabled Driver Adaptations Book

A revised third edition of Adaptations for the Driver is now available from the Mobility Information Service. The booklet, costing £1.25 including P & P, uses line drawings to illustrate a wide range of adaptations to cars from simple clip on modifications to major driver control systems. Leading manufacturers, importers and fitters are listed, with brief details of the services they offer.

The booklet can be ordered from Mobility Information Service, National Mobility Centre, Unit 2A Atcham Estate, Shrewsbury SY4 4UG.

Items mentioned in Product News have not been tested by Link

CHALLENGING BEHAVIOUR

Mr Steven Dorner is a clinical psychologist. He works for Portsmouth and South East Hampshire Health Authority. At a study day held at ASBAH's head office in February he came to speak about Challenging Behaviour and its Management in Young People with Hydrocephalus. This is a summary of his talk.

Before explaining the main management approaches to challenging behaviour we have to define what is meant by this term. Indeed it is probably not the best term to use for the behaviour problems sometimes associated with hydrocephalus as it is also used to describe the problem forms of behaviour experienced in residential institutions or by those who have been brought before the courts, rather than a child living with its family in the community.

Two definitions of challenging behaviour are:

Any behaviour which deviates from accepted norms - from self injury to unusual actions eg persistently pouring milk down a sink.

Behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to and use of ordinary community facilities.

Management approaches

Behaviour modification has been an influential technique since the 1960s. It looks at the context in which the behaviour occurs, what sets it off, what the behaviour is and what is the outcome. The approach is then to identify an alternative acceptable behaviour and reward and reinforce it while finding ways of ignoring the unacceptable behaviour. This is often an effective approach with its roots in common sense. However, it does need someone to systematically observe and then to decide how to go about changing the behaviour. In its early days aversive techniques were used in behaviour modification, for example, using a water spray to shock the child when he behaved unacceptably. These techniques gave rise to ethical problems about this approach but supporters of behaviour modification would say that you can change behaviour without resort to aversion techniques and most behaviour therapists now rely on *positive* approaches to changing behaviour.

Another management approach is that of **Functional Analysis**. This method involves asking four questions:

★ What is the behaviour that needs to be replaced?

★ What purpose does it serve - ie why is the child behaving in a certain way - showing off to get rid of a visitor for example.

★ What acceptable behaviour could serve the same function?

★ What needs to be done to support the development of the new behaviour?

If using this approach the parents and professionals need to collaborate closely. Parents know their child and should not refrain from putting their view across for fear of being 'impolite' to the professional helping them.

The first question in using this approach will be relatively easy to answer - you know which behaviour you find unacceptable - but discovering its purpose is not so straightforward. Several psychologists have suggested possible functions of 'challenging' behaviour, these include Carr and Durland who see it an an escape/ avoidance technique or attention seeking. Steven Dorner feels that children with hydrocephalus are more likely to fall into the first category. Clements gives four possible functions of challenging behaviour: social attention, escape/ avoidance, sensory stimulation or material rewards.

So having identified the child's purpose in behaving in a certain way how do you intervene? The intervention will need to be tailor-made for your child to be effective and can be split into four steps:

★ Specify the functional alternative ie what acceptable behaviour could one teach the child to use which would serve the same purpose.

★ Select reinforcers ie decide what will be rewarding to the child so that when they show alternative acceptable behaviour it can be rewarded.

★ Decide how reinforcers will be applied - they must be consistently applied and close to the time of the behaviour.

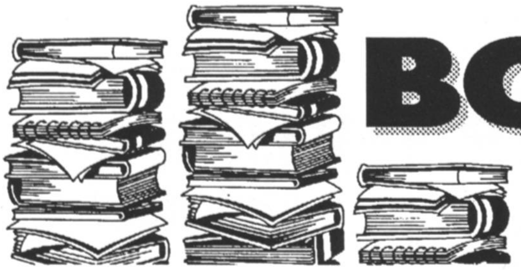
★ Ecological or environmental manipulation - try to change the circumstances to those which promote acceptable behaviour.

Having said all this, Steven Dorner feels that the 'challenging' behaviour associated with some hydrocephalic children is not typical of other groups but stems from a greater tendency for anxiety in these children. An Australian psychiatrist found that children with hydrocephalus who showed conduct disorder also had high rates of anxiety.

Anxiety heightens the child's perception of possible threat which they may then try to escape or avoid either by unacceptable behaviour, or by not doing something - in order to avoid being judged. This motivation *not to do* something is how Steven Dorner would see what is often described as low motivation in children with hydrocephalus.

The first step is to recognise that anxiety in children with hydrocephalus is common and often shows as 'escape or avoidance' behaviour. Clearly, professionals and parents need to work closely to help with this and consider how reducing the difficulty or complexity of what is required may ease things.

Secondly, there are well-tested approaches to anxiety management using relaxation techniques and gradual exposure to varying situations so that they can be experienced safely. Again, careful, co-operative planning of these approaches is essential.



BOOK REVIEWS

Disability in Britain

"The often-held perception is that in highly industrialised societies disabled people are 'well taken care of'. In Britain, disabled people know only too well that this is a fallacy."

So writes Henry Enns, of Disabled Peoples International, in his foreword to **'Disabled People in Britain and Discrimination: a case for anti-discrimination legislation'**, written by Colin Barnes (Hurst & Company, London, paperback, 264pp, £9.95).

He continues: "For years, they have struggled to bring their case to the attention of authorities who can change the situation. Their efforts have been thwarted time and time again. According to Nicholas Scott the Minister for Disabled People, discrimination occurs because of ignorance rather than ill-will. But this book shows, with hard facts, that good-will is not enough.

"Clearly, charity and social services are not enough to remove the discrimination that disabled people face in their societies. In Britain, the entrenched charity model has become a double-edged sword.

"Not only has it failed to attack discriminatory practices but it has developed the myth that disabled people are well provided for. This book provides hard and solid data for a statement of mine reported in the *Guardian* on 2 June 1986 that disabled people in Britain are in fact worse off than those in many developing countries.

"This is indeed a harsh reality that many are reluctant to face. Nevertheless, one needs to accept the facts if change is to be made. Those responsible for this book are to be congratulated for clearly portraying the facts as they are. In objective analysis, they paint a picture of the reality of disabled people in Britain. That picture is not very complimentary. It must be hoped that the stark truth of reality will motivate a war on institutional discrimination."

Colin Barnes has a hereditary visual impairment and for seven years attended special schools. He studied special education needs at Huddersfield Polytechnic and in 1989 obtained his PhD at Leeds University. He is a co-editor of the international journal 'Disability, Handicap and Society' and is principal research officer for the British Council of Organisations of Disabled People. TB.

... and in Europe

ASBAH chairman Patrick Daunt explores the intersection between the political integration of Europe and the social integration of disabled people in **'Meeting Disability: a European response'**, Cassells, London paperback, 215pp, £15.99 + £2.50 p & p).

The first head of the European Commission's Bureau for Action in Favour of Disabled People before retiring in 1987, Mr Daunt describes the situation of the 30 million or so disabled people in the European Community and sets out what has been learnt about their difficulties, achievement and aspirations.

He goes on to illustrate the extent to which official and voluntary initiatives (European, national or local) have succeeded or failed in responding to these needs.

No previous attempt has been made to present the problems, progress and prospects of the disabled citizens of Europe. TB.

Pride Against Prejudice - Transforming attitudes to Disability

By Jenny Morris, published by the Women's Press

Jenny Morris is a disabled feminist who states that this book is for disabled people: "A celebration of our strength and a part of our taking pride in ourselves, a pride which incorporates our disability and values it". As such, it is a refreshing, challenging read, if somewhat 'sociological' in tone. She takes a political, rather than medical view of disability and examines the forms "disabilism" or prejudice can take - beginning from an extremely disturbing historical perspective. Nevertheless, Morris takes pains to emphasise how liberating *not* denying the physical implications of a particular disability can be.

Her honesty in addressing the failure of feminism to fully explore disability issues lays bare the failure of society as a whole to allow disabled people to exercise fully their civil rights. There is an interesting discussion of many popular assumptions about disability which form the bedrock of much prejudice and misunderstanding.

Contributions from eight disabled women lend substance and colour to many of Morris's points. But it is Morris's conviction and anger which keep this book alive, without a trace of sentimentalism. Her frequent references to interesting research and her excellent bibliography are to be applauded.

I recommend this book to anyone and can only express dismay at the price of £6.95 for a paperback of less than 200 pages. RS.

Outward bound for adventure

Outward bound courses are often used by businesses to develop character and leadership qualities in their managers but these challenging outdoor experiences are also available to disabled young people. The Outward Bound Trust at Eskdale, in the Lake District, which runs courses for industry and commerce also offers the John Hawkridge Challenge for people with disabilities.

This course is described as every bit as challenging as the courses they provide for able bodied people, with activities such as canoeing, camping, rock climbing and, possibly, a self-sufficient overnight expedition. "Participants join a close-knit group working alongside other people with disabilities. This calls for self reliance, co-operation and a degree of independence."

John Hawkridge, who has cerebral palsy, approached the centre to suggest that there was a need for this type of course for disabled people and the JH Challenge became part of Outward Bound Eskdale's programme in 1989. John Hawkridge is an adviser for the course, which he feels gives disabled people "a chance to look at themselves as achievers rather than victims. To see what their capabilities are rather than their restrictions".
The JH Challenge is for those aged 16 to 30 years old and the fee is £285 plus VAT, which includes tuition, food, accommodation and equipment.

Separate courses are run for wheelchair and non-wheelchair users - with a maximum of six wheelchairs users on a course. They have limited accessible facilities at the Outward Bound base.

Contact Phil Kennett to discuss your particular needs, on an informal basis, tel 09467 23281, or write for details from Outward Bound Eskdale, Eskdale Green, Holmrook, Cumbria CA19 1TE.

SHARE MUSIC IN 1992

Whether you're a budding Nigel Kennedy or just a 'school recorder' player, a Share Music Course can accommodate you. All you need is a desire to make music and share in a variety of musical activities with musicians and helpers.

Share Music Courses are residential and run for one week. The cost is £150 which covers full board. They are open to anyone with a disability, from 17-40 years of age. Volunteer helpers are also needed, especially those with musical skills or experience of working with disabled people.

Richard Stilgoe, the well known TV entertainer, is a tutor on all three courses this year. The dates and venues are: Share Music North, July 18 to 25 at the Calvert Trust Adventure Centre in the Lake District; Share Music South, July 25 to August 1 at Crabhill House, Redhill, Surrey and Share Music Northern Ireland, August 9 to 16 at the Share Centre, Co Fermanagh.

Places are limited so early application is advised. Companions or relatives are welcomed and will be encouraged to join in the musical activities.

For more details contact: Dr Michael Swallow, 15 Deramore Drive, Belfast BT9 5JQ, telephone 0232 669042.

Summer Holiday for children

The Winged Fellowship is a registered charity which has five holiday centres in England. The centres usually cater for disabled adult holidaymakers but they also run two separate holiday weeks for children at Netley Waterside House overlooking Southampton Water. The next one is from 25 July to 1 August.

This is a 'traditional summer holiday' - swimming, day trips etc and is for unaccompanied children aged eight to 15 years. The centre provides professional nursing care 24-hours a day as well as volunteer helpers to accompany the children on outings.

For more details contact: Winged Fellowship Head Office, Angel House, 20-32 Pentonville Road, London N1 9XD. Tel: 071 833 2594.

A voyage of discovery

A new venture for the Winged Fellowship is Discovery Holidays - a variety of action packed holidays which range from conventional hotel based accommodation to camping. Venues include a coach-house in the Lake District, camping in North Wales or Cornwall, self-catering in the Highlands, hotels in the Cotswolds and late breaks at Centre Parcs. Prices are from £190.

There will *not* be a qualified nurse on these holidays but there will be WF volunteers and staff on a one-to-one basis.

More information from: Gary Day at WF Head Office (as above).

National Gallery gets access award

The Sainsbury Wing of the National Gallery has been awarded the 1992 Arts Access Award for "showing the greatest awareness of the needs of disabled people".

Minister for the Arts, Tim Renton (right), sits in the Award chair to chat with those at the presentation.

This is the first such award to be made by Arts Access - the National Association for Improving Arts Access for Disabled People. Already the Association has included sections in many British Telecom Phone Books giving details of accessibility of arts venues in the area - towns covered so far include Birmingham, London, Leeds, Manchester, Liverpool and Cardiff. This year they hope to have the information in eight more directories. Encouraged by the improvements on access they unearthed when revising the London Phone Book entries, Arts Access decided to make an annual national award, to lift awareness of the importance of making all arts venues as accessible as possible.

The Sainsbury Wing of the National Gallery provides a standard for others to aspire to, according to Peter Cooper of Arts Access: "Their whole approach is excellent from clear signs and total accessibility to the attitude of staff".

The gallery was presented with an electric wheelchair for use by disabled visitors.

Activity weeks abroad

A chance to meet others from all over the world, while learning new skills, is on offer to disabled young people who join a Mobility International activity week.

The projects are organised with young people aged 16-30 in mind but those over this age can also participate. Weeks planned for 1992 include

Discover Slovakia - from 28 June to 5 July - this will centre around the cities of Bratislava and Silenica with guided bus tours around the country, to the mountains, a visit to a health spa and a chance to meet local young people. Personal Relationships - to be held in Toulouse in October - is intended for young people with physical disabilities from the EC, among the topics covered will be medical information, self-awareness and beginning relationships.

More details about these and other projects can be obtained from Mobility International, 228 Borough High Street, London SE1 1JX.

Special breakdown package for disabled motorists

National Breakdown have a package of benefits designed especially for disabled motorists. There are two levels of service to choose from - Premiere and Premiere Plus. Both include nationwide recovery in the UK, roadside assistance, home call and free European cover. In addition, Premiere Plus offers caravan and trailer cover, legal aid/advice, chauffeur provision, overnight hotel accommodation, free 24 hour car hire and a message handling service.

From 1 April the scheme prices are: £51 for Premiere and £62 for Premiere Plus, disabled motorists do not pay the usual enrolment fee.

Non-drivers can also use the scheme as the car is covered, not the driver.

For more details contact Lisa Mace, Schemes Sales, National Breakdown, Freepost, Leeds, LS99 2NB, telephone 0532 393666.

Wheelchair insurance

The Freedom Policy (arranged through Chartwell Insurance) enables you to insure new or used wheelchairs against accidental damage, fire and theft and includes up to £100 expenses to 'get you home' following loss or damage to your chair. Cover costs £30 per annum.

A Freedom Plus policy is also available on new chairs only, to give extended warranty cover.

You can apply for the insurance, or obtain more details, through GBL - dealers and repairers of new and secondhand wheelchairs. Contact GBL at Units E4 & E5, Shield Drive, Brentford, Middx TW8 9EX, telephone 081 560 5380.

Can we help?

Our Disabled Living Services team get many letters asking for their advice on matters ranging from continence to benefits and education to mobility. Many of their replies could help LINK readers with similar queries. If you have a problem and would like some help from our DLS team you can write to 'Can we help' at LINK (address on page 3) Confidentiality will be maintained and no names or addresses will be printed.

Keep a check on it

I am 25 and have spina bifida. I use a wheelchair and live with my parents. When I was younger I had regular check-ups for my kidneys at the children's hospital but now I do not have to see any specialist. If I have a urine infection my GP gives me antibiotics.

If I used to go regularly to see a specialist but now do not go at all does that mean that I do not have a problem now?

Unfortunately, your situation is not uncommon. It is still important that you are checked by a urologist (a specialist in bladder and kidneys) from time to time. How often that is depends on your particular situation ie what type of bladder you have and the current state of your kidneys.

If you have recurrent urine infections it is important that a specialist doctor assesses why these are occurring. It could be that by changing your method of bladder management these will no longer be a problem.

Ask your GP to refer you. Information leaflets on bladder and bowel management are available from ASBAH. If you wish to discuss your situation ring Jane Williams at ASBAH House on 0733 555988.

Automatic benefits

I am presently receiving Mobility Allowance and Attendance Allowance. What happens when the new Disability Living Allowance comes into force in April?

You will be contacted automatically by the DSS, by letter, telling you that you have been changed over to DLA. You need do nothing.

Can I apply?

I am presently receiving Attendance Allowance but was turned down for Mobility Allowance. Can I apply for the new Disability Living Allowance - mobility component?

Yes - we advise clients to apply for the mobility component even when they have been refused in the past. Fill in the mobility component section of the form.

Forms can be obtained at the DSS Office, Post Office or by contacting the free helpline on 0800 882200

Unsatisfactory Statement

I have recieved a draft statement for my son from my Local Education Office. Unfortunately, I am not entirely satisfied with it as it does not seem to take into account the advice given in some of the assessments or the special needs of our child as we see them. What should I do?

A draft statement is sent to you for your comments before a final version comes into force. You have 15 days to comment on it and I should go through all the documents very carefully and make notes on any alterations, additions and clarifications you would like the Authority to make. Then seek a meeting, with the named person responsible for the statement at the Education Office, to discuss the things that you are not happy with. Should you wish to have the help of the Education Adviser at ASBAH send a letter to the Education Office to request an extension of the 15 days so that you can consult us for advice prior to the meeting. Usually the Authority will oblige.

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS

Rates: £3 for 30 words max; £4.25 for 30-45 words;
£5.50 for 45-60 words.
Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (June) should be submitted by Friday,1 May. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

FOR SALE

ARE YOU finding your present chair too heavy and cumbersome to use? You want a new lightweight chair, but can't afford the prices of new models. Have you ever thought of buying a secondhand or ex demonstration model? GBL SERVICES deal in all models of lightweight wheelchairs both new and used, tel 081 569 8955.

BROMAKIN RACING WHEELCHAIR. Medium frame, nylon upholstery. Seat 10.5" W, 13.5" L. 700c rear wheels with STD push rims. 8" front castors. Extension foot rest with tray. £400 ovno. Phone after 5.30pm. 0258 451758

1990 RENAULT EXTRA CONVERSION to transport a wheelchair passenger. Diesel, red, tinted side windows, full width access ramp, wheelchair clamps. Fully fitted interior with removable additional passenger seat. Renault extended warranty to May 1993. Price £7,850. Telephone 0246 850 890.

HOLIDAY ACCOMMODATION

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

SELSEY, SUSSEX
Fully-equipped, six berth mobile home, with colour TV, ramp access, all rooms designed for wheelchair access.
Site near sea, heated pool, also clubhouse and small shops. Details: Mrs C. Bugden, 27 The Grove, Sholing, Southampton, SO2 9LT. Telephone 0703 444921.

ROMNEY SANDS, KENT
Two bedroom holiday chalet, sleeps 6, fully equipped, wheelchair accessible, full club facilities, heated pool etc. Across road from beach. For details contact Jan Walton tel: 0892 832590

mar y sol

SUNNY TENERIFE or SCENIC NORTH WALES?
Holiday apartments at beautiful, fully accessible 'MAR Y SOL' Los Cristianos. "Brilliant, Amazing," say the BBC'S Travel Show. Flights arranged, also luxury adapted bungalow (sleeps 4/5) in Mold, Clwyd. Brochures: Lynne James Ltd, 7 Overpool Road, Ellesmore Port, South Wirral L66 1JW (Tel: 051 339 5316)

MAR Y SOL - TENERIFE
Lowest ever summer prices, wheelchair accessible apartments, heated pool with hoist, restaurant, poolside bar, equipment hire. Ring today for video and cheapest prices on flights and accommodation. Tel: 0753 685718. Sue Abbott, 123 Coppermill Road, Wraysbury, Staines, Middx. TW19 5NX

ISLE OF WIGHT ASBAH
Completely refurbished, fully equipped, wheelchair accessible 2 bedroom holiday chalet, sleeps 6 + cot. Clubhouse, indoor heated pool, shop, etc.
Site overlooks sea. Own transport advisable. Details: Mrs P. Burden, 34 Sherbourne Avenue, Binstead, Ryde, Isle of Wight PO33 3PX

BLUE ANCHOR, NEAR MINEHEAD.
Privately situated self-catering 2 or 3 bedroom bungalows, fully accessible fully equipped with linen, TV, video, games room, laundry, parking, playground. Splendid views of sea. Exmoor, steam railway. Phone: Lorraine or Martyn Baab, Dunster (0643) 821200 to discuss your particular needs.

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