

# Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

March/April 83



**New car badge: Special Motor Show: Answering Service:  
Photographic Competition: MSC Community Programme: Care of  
the feet: Perceptual problems.**

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# Link

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**Association for Spina Bifida  
and Hydrocephalus/ASBAH**

Correspondence to ASBAH at the National Office:  
Tavistock House North,  
Tavistock Square,  
London WC1H 9HJ.  
Registered Charity No. 249338  
Tel: 01-388 1382/5

**Patron:**

HRH The Duchess of Gloucester

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

**Chief Executive Officer:**

Miss M P Gilbertson, MCSP

**Finance Officer:**

Mr F G Armour, FCA

**Director of Appeals:**

Miss Judy Kay, MIPR

**Education, Training & Employment Officer:**

Mrs B Newman

**Disabled Living Advisers:**

Miss Mary Small, DIP COT, SROT

**Information Officer:**

Miss B Holland

**Link Editor:**

Mrs S I Gearing

## "I use a wheelchair"

IT HAS become increasingly apparent that the Orange Badge Disabled Persons Parking Scheme is no longer effective and appears to be extensively abused. One only has to look around to see the vast numbers of cars, etc., that display this badge.

Our aim is to create enough publicity to correct the misuse of the wheelchair motif. We have no wish to interfere with people using the parking facilities supplied for those holding the Disabled Permit, and indeed if anyone wants to have a "Disabled" sticker in the window of their vehicle then so be it. It is a matter for their own conscience.

We believe that the excessive availability of the Orange Badge has brought about a situation whereby most people do not give the necessary consideration to wheelchair users with motor vehicles, (i.e. leaving adequate room by doors for access). Therefore, by the issue of a new badge displaying the words "I use a wheelchair" and the wheelchair motif, solely to wheelchair users, we hope to help to rectify this situation.

We do not wish to cause any insult or pain to those people who are genuinely physically or mentally "inconvenienced" but do not use a wheelchair. As mentioned above our aim is to deal with the problem of parking, and access by wheelchair users to a parked vehicle.

### Private venture

We feel however, that we must point out that this new, "I use a wheelchair", badge is a private venture and is not financed or endorsed in any way by either the government or the Department of Health and Social Security. It has not legal authority and does not provide the holder with any legal benefit or privilege.

If you are the holder of an Orange "Disabled" Persons Badge, you are only legally required to display the small tax-disc sized certificate on your windscreens. Therefore the large Orange badge which is displayed voluntarily, often on the rear window, is not a legal requirement and may be removed in favour of the new red badge.

These new badges are being kept to a minimum price. However, to cover the cost of manufacture and the cost of letters and postage we would ask anyone wishing to obtain a badge to please contribute £1. A receipt will gladly be issued if required.

If you wish to obtain a new badge could you please send a stamped self-addressed envelope to either of us (names below) and a short questionnaire will be forwarded to you. The object of this questionnaire is just to establish that YOU ARE the user of a wheelchair.

Rev P H ROLTON,  
2, St. James' Way,  
North Cray, Kent.

Mr M BISHOP,  
96, Pattens Lane,  
Rochester, Kent.

### **... of The Wheelchair Association**

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**COVER PHOTO:** Archery — one of the most popular of wheelchair sports — being taught to a young member of Sussex Association at a weekend held by the local association at Hindleap Warren. PHOTO: Philip Ridler whose work has appeared in LINK before took this excellent picture and many others during this weekend, and during a weekend which was held by Sussex Association at Felbury House (see page 9).

### **1981 EDUCATION ACT:**

The remaining provisions of the 1981 Education Act come into effect on April 1. Please keep ASBAH informed about how the Act is interpreted in your area. Contact Barbara Newman.

While ever 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.

## Vitamin Trial starts in April

**THE CLINICAL Trial of Vitamin Supplementation organised by the Medical Research Council is due to start on April 1.**

The aim of the Trial is to find out whether giving certain vitamins to women 'at risk' prevents their babies from developing neural tube defects such as spina bifida.

ASBAH is maintaining close links with the Medical Research Council, and is particularly concerned that families who are considering taking part in the Trial should be fully informed about all the facts.

For this reason ASBAH is compiling a pamphlet of questions and answers about the Trial which should be available soon.

Meanwhile if you wish to discuss the Trial, or would like any further information, please contact Miss Rosie Horsfall, Disabled Living Adviser at National Office.

## No clamps for badge holders

**WHEEL** clamps are being used as a means of immobilising illegally parked cars for an experimental period in London.

However, the Government has made it clear that no clamps will be placed on cars displaying a current disabled persons' parking badge.

## Reports urges special help for disabled

**THE MANPOWER Services Commission** has published a report of its recent review of services for disabled people. The report stresses that disabled people should enjoy priority throughout all MSC programmes and that there is a continuing need for specialist advice.

Among other recommendations the report suggests: a regrouping of current services, so that disabled people could be helped by the mainstream employment service where appropriate; the specialist element of giving occupational advice and counselling should be concentrated on those in greatest need of help; and that advising employers and disabled people at work could be pursued more

## ASBAH'S Spring Conference April 8-10

**THERE'S still time to book for ASBAH's Spring Conference. It is being held from 8-10th April at Goldsmith's College in South London, the venue for the last Conference.**

The themes of Independent Living, Occupation and Accommodation should be of interest to a great many people.

Among the distinguished speakers is Gordon Holloway, General Secretary of the Shaftesbury Society, which has an extensive housing programme for disabled people.

There will be a talk about the South Wales Housing Project by Roger Hoad from the Family Care Housing Association and ASBAH fieldworkers in South Wales, Joyce Hodge and Tom Davies. There will also be speakers on other types of accommodation.

A demonstration and talk on how to make and adapt your own clothes will be given by Nellie Thornton from 'Fashion for the Disabled'.

The ASBAH volunteer programme and the DIAL Information Service will be featured, too, and Leonie Holgate, ASBAH's Mobility Adviser will be another speaker.

Young members of ASBAH will provide the entertainment on one evening, and there will be a disco on Saturday evening.

On Saturday, there will be a trade exhibition open to the public all day, together with an information leaflet stand from other organisations.

Closing date for applications is March 31. ASBAH hopes to see as many members and friends at the Conference as possible. Full details and an application form can be obtained from: The Conference Organisers, ASBAH at national office. Tel: 01-388 1382.

effectively through small specialist teams.

Copies of the report 'Review of Assistance for Disabled People' are available from MSC, Moorfoot, Sheffield S1 4PQ. Tel: Sheffield (0742) 753275.

## Training scheme draws up special rules

**THE YOUTH Training Board** (of the Manpower Services Commission) has recognised the special needs of handicapped young people in drawing up the eligibility rules for the Youth Training Schemes (YTS).

Originally the YTS was to be for all 16 year old and some 17 year old school leavers. However, after representations from a number of organisations, including the National Bureau for Handicapped Students, the Board has now recognised that many handicapped young people do not enter the labour market at 16 or 17.

Accordingly it has been decided that YTS shall be open to all handicapped people who at the age of 18 leave school or otherwise become available for work. They will also be able to stay on YTS for longer than the standard 12 months.

## Motability now offers better terms

**THERE** are now new and better terms for rental or hire purchase of cars under the Motability scheme.

Advance rentals for cars on lease have been reduced by about £80. Four cars are now available without an advanced rental, and for one (the Mini Mayfair) there is no insurance to pay whilst premiums remain as at present. Large credits are available towards insurance premiums for other cars.

Since November last year, a maximum of £3,029.24 can be provided towards the hire purchase of new cars. For used cars, up to £2,149.13 can be provided (cars up to 1299 cc).

Non-powered wheelchairs which help someone to stand unaided have recently been added to the forms of transport which Motability provides.

Please do remember that with this type of wheelchair as with any other, it is important to obtain medical advice as to whether it is suitable or not. ASBAH's Motability Adviser, Mrs Leonie Holgate, is available to give advice. Tel: Burgh Heath 56222 (every Thursday 9.30-3.30 pm) or write to her at: Banstead Place, Park Road, Banstead, Surrey.

## Motor Show for the Disabled

THE DEPARTMENT of Transport is organising a first ever Motor Show specially designed to be of interest to disabled people.

It is being held at the Transport and Road Research Laboratory at Crowthorne in Berkshire from May 19-21.

Disabled visitors will have the opportunity of seeing and test driving a wide variety of cars, to find out which is the most suited to their own needs.

Powered wheelchairs, vans, minibuses, hoists, hand controls and other equipment will also be on show.

For more information contact Yolanda Rizzi, at the Department of Transport, N19-14, 2 Marsham Street, London SW1P 3EB. Tel: 01-212 5257.

### Inquiry hopes to improve the role of the Arts

SIR RICHARD Attenborough is to chair a two year UK Committee of Inquiry into the Arts and Disabled People.

It aims to 'explore the extent to which existing facilities enable people with disabilities to involve themselves in the arts, both as participants and spectators, and having reviewed the present situation, make recommendations to encourage development and improvement'.

The Committee will invite evidence from people with disabilities, their organisations and those responsible for providing for

the arts. Its findings and recommendations will be published in a report accompanied by a book illustrating the various activities.

Further information from Carolyn Keen, Project Director, 15 Lodge Road, London NW8 7JA.

### Award Scheme is open for 1983

APPLICATIONS are now invited for the 1983 Snowdon Awards for Physically Handicapped Students.

The awards provide bursaries to enable disabled young people to take up opportunities for further education or training which otherwise they would have to decline or have great difficulty in taking up.

To qualify the candidate has to be

at least 17 and preferably under 25 years, although older applicants may be considered in special circumstances. He or she will have been offered further education/training and must demonstrate that financial circumstances coupled with the problems of disability are an obstacle to taking advantage of it.

Each bursary is for a period of one or two years and does not normally exceed £1,000 a year. Last year 16 awards were made.

The closing date for applications is May 31. Further information and forms from: Mr Eric Stonefield, The Secretary, Snowdon Award Scheme, Action Research for the Crippled Child, Vincent House, North Parade, Horsham, West Sussex. RH12 3DA. Tel: Horsham 64101.

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**FROM FRANCE, Germany and Norway have come letters from LINK readers wishing to make contact with families in this country.**

## International call for friendship

Jean Louise Dejean from the South of France is 27, has spina bifida and would like to correspond with some young English people to improve his English. His address is: Alles Iena, 76, Le Richlieu, 11,000 Carcassone, France.

Another request came from a 19-year-old German girl who has spina bifida. She says: 'I come from Esslingen, a town near Stuttgart in West Germany. Last year I wanted to spend my summer holidays in England and I looked through all the prospects I got. But mostly it was only travel, including English lessons, and I don't want to make 'language' holidays.'

My desire is to spend my holidays in a family with children. I think it's better that the family get information about my handicap. So I am looking for an English family with children, who are happy to receive a handicapped girl with spina bifida but who can walk and is independent. Greetings from Christiane Frick, Seracher Strasse 3, 7300 Esslingen/N, West Germany.

In the post, too, was a letter from a Norwegian family with three children, the youngest of whom has spina bifida. Some LINK readers may have met the family when they were over here recently and visited Five Oaks. They write: "We want to make contact with an English family for holidays and friendship. We are living in our own house with a garden about 3 miles outside Tonsberg. The ground floor is about 100 square metres and accessible for wheelchairs. In the mountains, 2,00 ft above sea level, we have a cabin — 2½ hours away by car."

We are both teachers and have four children — boy, 15, girl 13, girl 10 and boy 3. The youngest has spina bifida and hydrocephalus. The whole family are keen on scouting, and active participants in the protestant parish. We are around 40 in age.

If you are interested, please write to: Eva and Aksel Eivind Gilje, Hellav 9, 3140 Borgheim, Norway.



Seven-year-old Richard Kilburn being shown inside a motorway patrol vehicle by PC Doug Jacks (left), and PC Sandie Aiken. It was one of the stops for Richard, who has spina bifida, in a day with the police in Birmingham.

He wrote to the Chief Constable: 'Can I join the force if I learn to master my new calipers?'

As a result the police put out the red carpet for Richard — picked him up at home, showed him round headquarters, and treated him as guest of honour at a lunch with Chief Supt. Alan Leivesley, head of the community relations department.

Then Richard moved on to county traffic patrol headquarters, was shown inside the motorway patrol vehicle, and met one of the police alsatian dogs and his handler. All in all it was a wonderful day for Richard.

Photo: The Birmingham Post & Mail.



Jane Denness of East Grinstead receiving a special souvenir for becoming the 5,000th student at Portland Training College for the Disabled, Mansfield, Nottingham.

At a special ceremony, Jane, aged 17, of East Grinstead, Sussex, received the souvenir made in the college workshop from the President, Sir John Eastwood (pictured right). Also in the picture are College Chairman Tom Ashton, and Principal Ken Gill (centre).

The day a young man joined the Force and found they had rolled out the red carpet

## OT joins ASBAH as new DLA . . .

SPELLED out properly, this means that ASBAH has recently welcomed a new member to its Disabled Living team.

Miss Mary Small, a qualified Occupational Therapist, has joined Rosie Horsfall as a Disabled Living Adviser working from National Office. Mary, who comes from North of the Border, looks forward to meeting as many families as possible.

# answering service

your questions answered by experts



I have a ten-year-old child suffering from spina bifida, and who is incontinent. My washing machine has finally broken down completely and I cannot afford to replace it. Somebody told me that the Family Fund might help me. Can you tell me what is

The Family Fund and how will it help me?



The Family Fund was set up to help families caring for a severely disabled child. Applications can be considered from any family in the United Kingdom provided that the disabled child is over two years old and not yet 16.

Help may take the form of goods, such as washing machines, services or a grant of money for some definite purpose related to the care of the handicapped child.

When your application is received a representative of the Family Fund will call upon you to discuss things. In the case of a washing machine the Fund has a list of models from which a choice can be made, if your application is approved.

Application should be made to: The Family Fund, PO Box 50, YORK, YO1 1UY.



My cousin recently gave birth to a little girl and she has been told that the baby has hydrocephalus. She read the book she was given which tells her what this means, but she really wants to talk to someone about this. She feels that she will not be able to look after the baby and needs some of her questions answered.



ASBAH has Fieldworkers in some parts of the country and their support may help a family to cope with particularly difficult times, especially in areas where Social Services are under pressure.

If your cousin contacts our National Office we can tell her whether there is a fieldworker in her area, and how they may help.

She may also be interested to know that there are local associations in most areas and we can provide details of her nearest group if she wishes.



We are a one-parent family on Supplementary Benefit and I find it very difficult to manage on the money I get. It costs a lot to keep the house warm as my little boy is disabled and gets very cold. Is there any way I can get some extra money to help me to manage?



You should ask your Supplementary Benefit Officer whether you are entitled to extra benefit for your special needs.

It is possible to get regular weekly additions which are called 'additional requirements' if you satisfy the conditions laid down by the Supplementary Benefit (Requirements) Regulations.

Subject to these conditions, the regulations allow additional requirements to be awarded for such things as heating, baths, etc.

If you prefer it, of course, you could ask your Social Worker to help you to find out about these extra payments.

Please remember that ASBAH National Office Staff are always happy to answer any queries you may have and you can contact us on —

01-388 1383

or write in to — Tavistock House North, Tavistock Square, London WC1H 9HJ.

*Teresa Cole — Fieldwork Coordinator*



## Project Leader for Five Oaks

THE CHANGING and developing role of ASBAH's Centre at Five Oaks is reflected in the new post of Project Leader which has been created there.

Mr Jim Stanton has been appointed Project Leader and his task is to develop the services of Five Oaks, including the training programmes for children, young people, parents and professionals, in all aspects of the management of spina bifida and hydrocephalus.

ASBAH members will have the chance of meeting Mr Stanton at the Spring Conference. He was formerly project leader of an Adventure Playground at Moseley.

Miss Joan Pheasant, already known to so many families, has become Head of Care Staff at Five Oaks.

THE MAJOR event of the year for Bromley and District Association — its Christmas Party — was held at the end of January, for members and friends.

Once again it proved an enjoyable get-together. Entertainment was provided by a children's entertainer and two bands, one of which was a children's band from Charlton Park Special School. There was even a face painter!

The surprise of the afternoon was an appearance by Michael Robins (from 'On the Buses'), and some of the cast from the Babes in the Wood show at the Churchill Theatre.

Stars and Bromley Association party-goers line up for the camera.

## Yoga weekends for disabled

TWO special family weekends of yoga for the disabled are being held this year at Ickwell Bury, the residential centre of the Yoga for Health Foundation.

The weekends are over the Bank Holidays: April 29-May 2 and May 27-30. Children are welcome at special reduced prices and there will be holiday activities as well as yoga sessions. The aim is to provide families with a real opportunity of relaxing.

Disabled guests are welcome at all times at Ickwell Bury, and from Sunday, July 22, there will be a one week holiday for the disabled and their families.

For full details please contact: The Yoga for Health Foundation, Ickwell Bury Residential Centre, Northill, Biggleswade, Beds. (Tel: 076-727 271.)



Get out and about with the Speedwell Supakart.

Designed primarily for physically handicapped but is suitable for all children from 6 to 16 years of age who have reasonable strength in their hands and arms.

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:  
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SLOUGH, BERKS.  
Telephone: SLOUGH 72249

***Get out and about with the  
SPEEDWELL SUPAKART***

A winning picture — taken by Ann Wild, 9, who has spina bifida. It won her the Jubilee Trophy in the 1982 Annual Exhibition of Photography for the Disabled.

Below, blindfolded pushers during an obstacle race for young people from Sussex Association on a weekend holiday course at Felbury House.

A good example of action photography by Philip Ridler, who himself has spina bifida.



## A wedding picture for the album

A happy wedding picture recently sent to LINK by Greenwich and District Local Association.

One of the original members of that association, Jackie Page was married to Philip Parkinson at St Mary's Church, Woolwich last year.

Philip and Jackie have a home of their own in a flat specially built by the local council.



## Photography clicks for the disabled

**THE ANNUAL** Exhibition of Photography for the Disabled brings out some remarkable work by disabled photographers of all ages.

Last year was no exception, and one of the most notable winners was a young nine-year-old girl with spina bifida, Ann Wild from Chigwell, London. With her excellent eye for subject, composition and lighting she won three trophies. One of her winning pictures is shown left.

It is time for entries for this year's Exhibition — so why don't some of LINK readers have a go!

There are classes for prints and slides, and both colour and black and white work. Usually any subject is acceptable, but for the Deanne Shield the subject is flowers. There are junior classes, too. By the way you don't have to process your own work — you can get a shop to do that.

You have until June 11 to get snapping, and if you would like an entry form and more details contact The Exhibition Secretary, 190 Secrett House, Ham Close, Ham, Richmond, Surrey. (Please enclose sae.)

This competition, which is open to any disabled person, is organised by Photography for the Disabled, a national registered charity. Its work is to encourage photography by people with disabilities and to this end it has been involved in several technical breakthroughs which make photography possible for even those with the severest handicaps.

For over 14 years it has made a speciality of adapting to cameras and supports fitted to wheelchairs, and has received hundreds of enquiries for a left-handed camera. Now there are two models which can be left hand controlled produced by the Konishiroku company.

For someone with no mobility at all, Photography for the Disabled has designed a suction operated camera.

If you would like more details about this organisation, write to the Secretary at the Richmond address (above).

MUCH HAS been written about unemployment amongst disabled people, less about a more acute problem—long term unemployment. Yet over 87,000 people identified as disabled are not only unemployed, but have remained unemployed for a year or more. Long term unemployment is a good deal more common amongst the able-bodied, and the numbers affected are rising fast.

What does long term unemployment mean to the people who experience it? Although every person's reaction is different there are a number of common effects. Long term unemployment marks the end of the (often unrealistic) optimism that often accompanies the earlier periods of unemployment; the idea that you will easily pick up another job gives way to the (often equally unrealistic) feeling that you will never work again. Long term unemployment means a long period on low income for yourself and your family; this in turn brings material hardship and psychological strains. Long term unemployment also means being cut off from your normal environment; work not only provides us with income, it also provides us with a culture, colleagues and friends, and a time structure to the day. The absence of these explains the feelings of listlessness and isolation that many long term unemployed people experience and the fact of long term unemployment is itself a disadvantage when it comes to applying for jobs—an applicant who can produce a recent reference is often preferred to someone who has not worked at all for a year or more.

There is no doubt what the solution to long term unemployment is; and that is the same as the solution for unemployment generally—the creation of secure and productive jobs. When, and how fast, we can secure more jobs in the economy is not clear, but it does seem unlikely that any up-turn in the general economy will have a dramatic effect on unemployment.

Moreover, even if the unemployment totals started to diminish, we can expect those who have been out of work the longest to be amongst the last to be re-absorbed into the workforce. All this means that long term unemployment is going to be with us on a considerable scale for some time.

## In the midst of long-term unemployment, MSC Community Programme offers ray of hope

**John West of MSC's Community Programme Branch explains a New scheme.**

But the fact that any permanent solution to long term unemployment inevitably lies some distance in the future does not mean that there is nothing we can do here and now to alleviate the effects on individual people. Although we cannot create permanent work we can provide temporary work, outside the normal economy, which can give real relief to long term unemployed people and which for some can hold the key to a return to normal jobs.

### *The Community Programme*

Using funds set aside by the Government, the Manpower Services Commission (MSC) has recently embarked on its largest ever programme of direct job creation. This new initiative is called the Community Programme. The idea is to create over the next year—130,000 temporary jobs involving work of community benefit. This is a fourfold expansion of the earlier CEP (Community Enterprise Programme). Many of the best known MSC schemes (such as the Youth Opportunities Programme) are directed at school leavers and young people. But the Community Programme is specifically for adults—people aged 18 or over who are long term unemployed. Very many unemployed disabled people are in the older age ranges, so the Community Programme can and should be of direct relevance to them.

What is the Community Programme? At its simplest it's a way of bringing together long term unemployed people and jobs that need to be done in the community. What do we mean by community jobs? Really anything that can be shown to be of benefit to a local community. Examples have included converting derelict sites into playgrounds, restoring churches or

ancient monuments, advising old people how to keep warm during the winter, and indeed surveys into local access problems for disabled people. The list of potential projects is literally endless. The important things are that projects should not involve private gain and should be clearly *additional* jobs—not just substituting for work which would in any case have been done.

With a few exceptions only long term unemployed people can qualify for a place on a Community Programme project. For disabled people this means that you need to have been continuously unemployed for 8 months (or 4 months if you're under 25); for able-bodied people the qualifying times are rather longer.

Workers on projects receive the local "rate for the job" applying to the type of work they do. Many (but by no means all) of the places on Community Programme projects are part-time (anything between 2 and 5 days a week) so actual weekly wages vary a good deal, but provided workers claim the benefits to which they are entitled (such as Family Income Supplement) they will certainly get more money than they did on the dole.

A person cannot stay on the Community Programme for more than a year. One of the reasons for having this limit, of course, is to spread the benefits of the programme amongst the maximum number of people, but also we think that after about a year a person should be trying his luck on the ordinary jobs market again—it would defeat the whole point of the exercise if the programme was confined to a set number of people who stayed year in, year out.

Two points are important to realise about the Community Programme. Firstly, it is real work; which means that ordinary work disciplines are expected and that participants are treated just the same as any ordinary employee. Secondly, and this is quite crucial, is that the programme is



Cataloguing customers and recording exhibits at Warwick Museum — a Community Programme project.

provided, not by the MSC, but by sponsors.

#### Sponsors

A sponsor is the person or organisation who thinks up a project, applies for MSC support, and who takes responsibility for the project once it is running. In effect the sponsor is the employer; of course the sponsor can employ managers and supervisors (paid for by MSC) to help his project.

While some sponsors like to contribute some of their own resources to a project (eg premises or extra materials), the Community Programme is designed in such a way that the smallest organisation can sponsor a project without any extra cost to itself (apart from some time, energy and enthusiasm).

In essence the MSC pays for the wages of a mixture of full and part-time employees, the wages of necessary managers and supervisors. The costs of employers' National Insurance payments are a per capita allowance for the costs of materials and overheads.

Local authorities are the largest single group of sponsors, but voluntary organisations also account for a large number of schemes. The range of voluntary organisations involved in the Programme is very large—from major national bodies to small community groups, sometimes set up specially in order to sponsor a project.

#### The Programme helps disabled people

The Community Programme can be useful to disabled people in two entirely different ways. First, projects could be set up for long term unemployed people, which are designed to help the disabled. We

have quite a few examples of this type of project—providing escorts and helpers for disabled people, decorating their homes or improving physical access—and of course projects of this kind can be of enormous benefit, and help voluntary organisations achieve their aims very much faster than they would otherwise have been able.

#### Disabled people who want to work

But even more valuable, we think, is to use the programme directly to bring relief to the very many long term unemployed disabled workers. For a job on a Community Programme project can represent an immense boost to a disabled person who has been out of work for a long time. How will it help him? Firstly, extra money—perhaps not that much extra if the job is a part-time one, but even a few extra pounds can make a lot of difference if you've been on low income for a long time; and many people will be markedly better off than on the dole.

But extra money is only the start. Working on a project gives a person the sense of doing something worthwhile; it restores the habits and disciplines of work which may have been lost during prolonged unemployment or sickness. People regain their confidence as they rediscover their old abilities or learn new ones (training, formal or informal, is an important part of many projects). And when the time comes to leave a project you have a recent reference which may well make all the difference when you apply for other permanent jobs.

So the programme can bring real benefits to unemployed disabled people. But, how do we make sure that as many people as possible get the chance of joining the programme? Of

course we at the MSC will be doing all we can to put disabled people in touch with opportunities, and to encourage sponsors to recruit disabled people to projects. But the most direct and effective way to secure the opportunities—and opportunities which are relevant to disabled people—will be for organisations concerned with disabled people themselves to become sponsors of projects.

Some disability organisations are already doing this, but there is plenty of scope for more. Of course projects do not need to employ a workforce wholly made up of disabled people, and some sponsors will doubtless want to have a mix of disabled and able-bodied people. On the other hand the MSC will welcome all-disabled projects if this is what a particular sponsor thinks will work best for him. And of course we will welcome projects which include opportunities for disabled people as scheme managers and supervisors as well as participants.

Voluntary bodies concerned with disability have a long and proven track record in running and managing efficient services for their members. That is why we at MSC are so anxious to harness this organisational ability and experience in the context of the Community Programme. These voluntary bodies also have considerable expertise in helping people with certain disabilities and we hope that one of the spin-offs will be that voluntary bodies will go further than simply sponsoring projects for disabled workers and will also organise counselling, advice and training for the people on their projects. Indeed the programme could be used as a means of setting up some interesting and experimental approaches to integration and rehabilitation.

The Community Programme offers a wealth of opportunities for individual disabled people and organisations serving them. We at MSC hope that full advantage will be taken of these opportunities. If you want to know more about the Community Programme, pick up a leaflet at your local job centre. Alternatively write to:

Community Programme Branch (ESU), Room W802, Manpower Services Commission, Moorfoot, SHEFFIELD, S1 4PQ.

**This article first appeared in 'Contact'**  
**the magazine published by RADAR.**

**BASIC FOOT CARE** is essential for healthy feet and should be as much a part of daily hygiene as combing hair and brushing teeth. People with spina bifida may have extra problems which make it even more important for them to look after their feet carefully and if they are not able to do this themselves, then they should ensure that someone else does it for them. These extra problems are lack of feeling in the feet and poor circulation.

Lack of feeling in the feet makes it impossible to feel whether shoes are comfortable or the bath water is too hot and it is easy to injure the feet accidentally. Once injured, poor circulation means that the sore takes a long time to heal, shoes cannot be put on and mobility is limited.

Washing feet daily is important because they are warm and moist and usually kept covered — ideal conditions for bacteria to thrive in. The water should be warm 40°C (105°F) and the temperature should always be checked before putting the feet in (this applies to baths too). This temperature will feel warm to a hand or elbow but for complete safety, a thermometer should be used. Care must be taken to rinse off all the soap as particles left on the skin can cause irritation and drying must be thorough. A light dusting of talcum powder may be used to absorb any left over moisture. It may be difficult to dry one's own feet when sitting in a wheelchair and there is a danger of overbalancing. It is better to transfer to a safe area like a bed to do this.

If the skin is dry and flakey, it is better to rub in a little cream instead of using talcum powder. An unperfumed moisturising cream is suitable (like E45) or hand or foot cream can be used.

If the skin is soft and moist, a little surgical spirit rubbed in after each washing for a couple of days will help to harden the skin. Applications of surgical spirit should not be used over long periods as it may make the skin dry out too much and begin to crack. This treatment can also be used to harden the skin a little before wearing new shoes as all shoes take a little while to soften to the shape of the foot and they may rub during this period. Another precaution to take with new shoes is to wear them only for short periods at first so that the feet get used to them gradually.

It is important to examine the feet each day for any signs of damage or pressure. After washing them is a good time to do this or when taking shoes off in the evening. Angled

THE importance of daily care of your feet by Mrs J Hughes, MCSP.

*Mrs Hughes' book Footwear & Footcare for Disabled Children was mentioned in the last LINK. It is available from the Disabled Living Foundation, 43 East Hill, London SW18 2QZ. Price £5.25.*

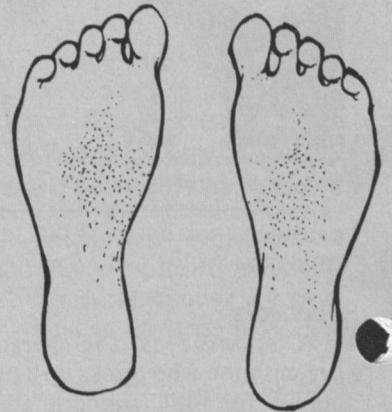
mirrors can be used to examine difficult areas like the backs of the heels. Signs to watch for are reddened areas which do not fade rapidly (unlike the mark made by a watch strap which disappears soon after the watch is removed), bruising, or red swollen patches particularly round the nails. Any signs like these should be pointed out to a nurse or doctor as soon as possible.

Because it is difficult to feel whether boots or shoes are comfortable they must be checked every day before they are put on to make sure there are not stones inside or nails sticking up through the sole. It is also important to make sure that they are on properly. It is quite possible for the toes to be curled up under the foot without being felt as the boot or shoe is put on so this must be watched for and corrected if it happens.

It is the blood circulating through the foot which keeps it warm and free from swelling so the problems caused by poor circulation are coldness and swelling of the feet and ankles. The muscles in the calf move the ankle up and down but as they do this, they also help to pump blood back up the leg to the heart. If the ankle is not moved, due to weakness or paralysis, circulation is made difficult and the foot tends to become cold and swollen.

Anyone who spends most of the day sitting should try to put their feet up for a short period each day to help the swelling go down. Just resting the foot on a stool in front of the chair will not help as the feet will still be the lowest part of the body. Ideally, the feet should be higher than the knees and the hips so that

## Foot Notes



### Care of the feet

gravity can help the circulation to recover and this means putting the feet up on something slightly higher than the chair being sat on. Care must be taken that the whole leg is supported while doing this and that the knees are not being strained by being over-straightened.

Anything that further limits the supply of blood to the lower leg and foot should also be avoided, for example, socks with tight tops, sitting cross-legged or wearing garters.

Pressure sores occur when blood is stopped from flowing through an area by extra pressure. The weight of the foot pushing the sides or back of the heel down on a hard surface can cause a sore and a wrinkle of a sock pressed on all day by a shoe can have the same effect. It is very important therefore, to move the foot every hour or so to relieve any constant pressure and to smooth out wrinkles in socks and stockings when they are put on. For this reason it is better not to wear socks with patterns or ribbing over the foot as this can exert an uneven pressure when enclosed by footwear.

Socks with no heel shaping may

also give rise to problems as they may wrinkle excessively over the front of the ankle and also press unevenly when enclosed by a boot. They are, however, very easy to get on as there is no right or wrong way round so if they are worn, this is a point to watch out for.

Keeping the feet warm is also important. Thick warm socks will help to do this but the whole leg must be kept insulated or heat will be lost on the way down to the foot. Trousers or thick tights are therefore a good idea plus warm footwear. Sheepskin bootee style slippers are ideal for keeping the feet warm when sitting and many readers will be familiar with the lace-up bootee

made by Antartex. Unfortunately, these are no longer available. There are patterns for making one's own slippers out of off-cuts of sheepskin or an old sheepskin coat. See pattern on this page and notes in end column or contact the Clothing Adviser at the Disabled Living Foundation (send SAE for details). There is also a company who make sheepskin bootees to measure and their address is listed below.

Another part of regular foot care is nail cutting. If this is not done carefully, it is possible to damage the nail and allow it to get infected. Nails must be cut to just inside the length of the toe (too short is as bad as too long). They must be slightly rounded, following the contour of

the toe but not cut down the sides as this can leave splinters of nail which can grow into the toe.

Because of the risk of infection to the feet it is better to use nail clippers rather than scissors but this is an area where help may be needed. If any difficulty is experienced in nail cutting, it is advisable to seek the help of a chiropodist who will also be able to advise on other aspects of foot care.

**Addresses:** Clothing Adviser,  
Disabled Living Foundation, 346  
Kensington High Street, LONDON  
W14 8NS.

John Wood & Son Ltd, Linton,  
Old Cleeve, MINEHEAD,  
SOMERSET TA24 6HT.

AN AMERICAN idea, being tried out in this country, is a Matrix Body Support System. It was on display at NaideX but may have looked rather complicated to the uninitiated!

It is a matrix system for a chair which — once you know how — can be easily changed and moulded to fit individual shapes. It could prove a very good idea for people suffering from bad spinal problems and pressure sores. It can be easily fitted into a wheelchair or pushchair as well as being a static seat.

The manufacturers are hoping that it will be available from the DHSS for use in hospitals, but some hospitals are buying it now to try it out, so if you are a therapist at a hospital or school it might be worth making enquiries.

More details from: Hugh Steeper (Roehampton) Ltd., 237/239 Roehampton Lane, London SW15 4LB. Tel: 01-788 8165.

## Disabled Living News

SHEEPSKIN bootees (see illustration) that open right down to the toe can be very useful and warm for children in wheelchairs. Here is how to make them yourself from parts of an old sheepskin coat.

Each boot consists of three pieces, — sole, sides and tongue, and it is not difficult to cut your own pattern. Holes are punched with a leather punch, and the number will vary according to the size of boot. To strengthen the holes you can stick strips of lightweight leather or other fabric about  $\frac{3}{4}$ " wide along the length of the opening. You need button thread, a leather work needle, and a pair of laces.

This idea came from Ann Cooke,

Senior School Physiotherapist from Chichester.

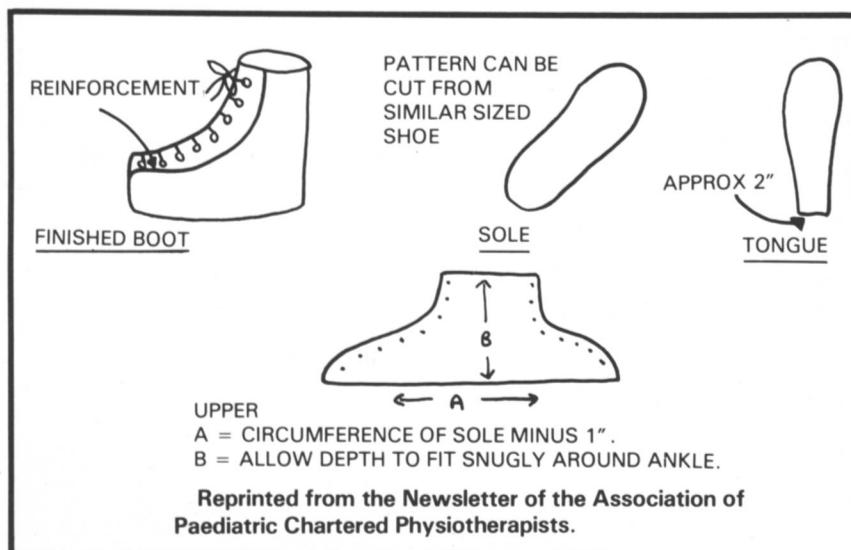


A puncture-proof tube for wheelchairs and bicycles has been manufactured by a firm in Horsham, Sussex, called Proudline Associates Limited. The tube called 'No-Morflats' which replaces the inner tube of a pneumatic wheel is easily fitted into a standard tyre mounted onto the wheel rim, and is made of a special rubber compound.

The tube, priced from about £9, is available direct from Proudline Associates Ltd, 2 Percy Road, Horsham, W. Sussex RH12 2JN. (Tel: Horsham 0403 53652), or one of their local agents. Proudline has submitted the tube to be tested by the DHSS, so in future it may be available through them.



A happy smile from Louise Treadwell, of Shrewsbury, as she travels back home in the coach after a swimming event at Harrow baths where, as a member of the Shropshire Sharks she won a Gold Medal in the relay race. Louise will be 12 this month (March) and walks with the aid of calipers. This picture and a letter about Louise's courage was sent to LINK by a 73-year-old admirer Mr. F. A. Porter.



# Pressure Sores?

## Let a RESTON cushion take the strain

Pressure sores need never happen. They can be prevented with the right sort of care and by using a reliable, good quality wheelchair cushion which really does relieve pressure without letting you down – literally! Water and air filled cushions may be easily punctured and lose their effectiveness whilst ordinary foam doesn't meet the test of 12 hours per day continuous use.



© 3M and Reston are Trade Marks

The "Reston" floatation cushion spreads your weight evenly and eliminates troublesome pressure points. Made from a unique gel material, it is comfortable, robust, easy to clean and fits securely into any standard wheelchair. You can even use it in bed. Hospitals throughout the world have proved that it really does prevent the development of pressure sores.

This is the first time that the "Reston" cushion has been generally available to the public. Up until now, it has only been available to hospitals.

Simply fill in the coupon below and send it to us, together with your cheque. The "Reston" pad is VAT exempt if your order is accompanied by a doctor's certificate. If you don't find the "Reston" pad an improvement on your old foam cushion, just send it back, clean and in its original box, within 21 days and we will gladly refund your payment.

Return this coupon to FREEPOST 3M Health Care, 3M United Kingdom PLC, 3M House PO Box 1, Bracknell, Berkshire RG12 1BR

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**3M**

## Positions for Play

FROM the Toy Libraries Association, comes this excellent booklet which gives ideas and advice on how to position handicapped children in order for them to play easily and effectively.

It is aimed at parents, toy library organisers and others working with physically handicapped children. Price 95p (including p and p) from The Toy Libraries Association, Seabrook House, Wyllyotts Manor, Darkes Lane, Potters Bar, Herts. EN6 2HL.

## Living Independently

THIS BOOK looks at the lives of nine severely disabled people who have established homes of their own in the community, and at the implications of these experiences for housing and support services and their costs.

Most people with severe physical disabilities rely on 'able' relatives to live in their own homes. Others who cannot call on this kind of help often find that their only alternative is a move to a residential home.

These nine people are different. Their disabilities are very severe and they cannot depend on 'able' relatives; yet they are determined to maintain a home of their own. Descriptions of their daily lives show the variety of help they have drawn on and how hard they had to work to find it.

This book challenges policy makers, architects and people working in statutory and voluntary services to look again at their assumptions about what is possible for people with very severe

## Reading matter

disabilities. It challenges them to recognise that the greatest barriers to independent living may not be physical disabilities, but the barriers created by regulations and bureaucracy. It shows that many other severely disabled people could, with support they choose for themselves, have what most of us take for granted — a home in which they can live a life of their own.

It is published by the Centre on Environment for the Handicapped and King Edward's Hospital Fund for London. Price £5.00 including p and p, from CEH, 126 Albert Street, London NW1 78NF.

### *Access at the Channel Ports*

HAVING produced guides to a number of areas across the channel, the Pauline Hephaestos Survey Project team has now turned its attention to the crossing itself. This publication gives information on each cross-channel ferry operator and port facilities, as well as a good deal of other general information.

Price 25p to cover postage costs, from: RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400.

### *Access to the British Museum*

AN INFORMATION sheet for Disabled Visitors to the British Museum is available free from: The Education Service, British Museum, London WC1B 3DG. Guided tours of the galleries can be arranged for groups.

## Pre-menstrual tension — Is it a problem?

### THE MEDICAL and Disabled Living Advisory

Committees of ASBAH are considering the need for a research project into the effects of pre-menstrual tension in girls with spina bifida and hydrocephalus.

Disabled Living Advisers have become aware, through contacts with schools, colleges and individuals that pre-menstrual tension seems to cause particular problems for a few teenage girls with spina bifida and hydrocephalus. Marked changes have been noticed in their level of performance with an exaggeration of any existing problems shortly before a menstrual period, and a return to a normal performance for that individual once the period has begun.

Some particular symptoms seem common — disorientation, lack of co-ordination, disorganised

behaviour, increased anxiety, emotional behaviour and physical problems such as fluid retention, a worsening of skin problems such as pressure sores and acne, and urinary diversion appliances failing to adhere to the skin as well as usual.

Symptoms appear to be particularly marked in girls who have an irregular cycle. They and those caring for them may be unaware that these changes herald a period.

ASBAH would like the opinions and comments of parents and others working with girls with spina bifida and hydrocephalus. If you are able to provide any examples from your own experiences it would be helpful to know whether the girl has spina bifida, hydrocephalus or both conditions, and her age. ASBAH does not wish to know the girl's name or other details. Opinions by letter or telephone would be welcomed. Please contact The Disabled Living Advisers at National Office.

### DLF Music Advisory Service

THE Disabled Living Foundation produce several resource papers of interest to disabled musicians.

MP17 "Ideas and Books about Musical Games and Quizzes", 30p plus postage.

MP2 "Organisations and Individuals concerned with Music and Disabled People", 30p plus postage.

MP3 "Working in Music with Handicapped People & Training Available", 70p plus postage.

MP7 "Music for One Hundred Pianists", £1 plus postage.

In addition the DLF is starting a newsletter, Music News, which they hope will serve as an information exchange. The first issue is available on receipt of an sae.

For above papers and other information contact Daphne Kennard, MBE, LRAM, LTCL, ATCL, Music Adviser, The Disabled Living Foundation, 346 Kensington High Street, London W14.

### ● STOP PRESS

Abled-bodied and disabled crew members are needed for ocean going holidays (weekends up to 2 weeks) on the *Soren Larsen* — the flagship of The Onedin Line TV Series. The cost is very reasonable.

Details: Jubilee Sailing Trust, Tavistock House North, Tavistock Square, London WC1H 9HX. Tel. 01-380 0160.

# Perception and the spina bifida child

IT HAS been observed by several writers that spina bifida children are likely to have problems of a perceptual nature.

This is noticed in the confusion which some spina bifida children have in dressing, positioning and generally assessing right and left. Some have noted a lack of appreciation of the body in space, evident in standing and walking, and refer to the tendency to reverse letters and words and to be confused with respect to lines of print or diagrams.

Others have observed, particularly with regard to children who also have hydrocephalus, that they have more problems with visuo-spatial perception<sup>1</sup> than those without this condition. There is also evidence that the Arnold-Chiari malformation of the cerebellum, closely associated with the spina bifida condition, can produce upper limb dysfunction in the form of paralysis and incoordination which in turn causes lateral confusion<sup>2</sup> and loss of fine finger control. It has been noted that it is more likely that spina bifida children will have a measure of visual impairment, this being possibly due to the effects of hydrocephalus.

In view of the possibility of spina bifida and hydrocephalic children having perceptual problems, it is understandable if they encounter difficulties in their educational development, for example with respect to the early stages of learning to read, to write and to copy shapes.

In a study\* primarily designed to consider the early development of mathematical concepts in spina bifida children, the writer, taking the view that perceptual development was an important factor in the formation of these concepts, investigated the performance of a group of 130 such children on two tests designed to assess their perceptual maturity.

The first of the two tests was Raven's Coloured Progressive Matrices, a perceptual test of intelligence and the second the Bender Gestalt Visual Motor Test which is associated with such aspects of intellectual development as visual perception, manual motor ability, memory, spatial concepts and organisation of representation.<sup>3</sup>

The results reflected a noticeable measure of perceptual immaturity on each of the tests, although the deviation from the norm was not as great on the Raven's C.P.M. as on the Bender (fig.1). Since the first test is related to visual-perceptual reasoning and the second to visual-motor<sup>4</sup> co-ordination the results suggest that the motor element in the Bender is an important factor in the sample's performance.

The figure (right) illustrates a marked deviation from the standardised norms on both of the tests, this being particularly noticeable during the early years in school when the foundations of educational skills are being laid.

The Bender Gestalt examines the following aspects of visuo-motor development: distortion<sup>5</sup> and rotation<sup>6</sup> of shape, integration<sup>7</sup> and perseveration<sup>8</sup>. Overall some 40% experienced difficulty with respect to shape and orientation; for example squares and circles were excessively misshapen and where relevant were disproportionately sized. Where dots were required to be

- This article is based on the doctoral studies of Dr Vernon Parfitt, supervised by Dr David Green. The director of research was Prof A. C. Bajpai, the Director of the Centre for Advancement of Mathematical Education in Technology at Loughborough University.

drawn, some children drew small circles. Children frequently inserted too many or not enough angles when required to draw polygons.

Some problems were observed in the orientation of some of the drawings, i.e. figures were drawn at angles which were more than 45 degrees from the original horizontal axes. In the tests where it was necessary to join or intersect figures the children frequently overlapped where it was important to just touch, or on the other hand, where they should intersect they often failed to meet. One test demanded two lines to intersect approximately in the centre; some children however frequently failed to make the lines cross and some others' lines crossed at the ends.

There was a clear and substantial correlation between the results on Bender and Raven's Matrices despite the different aspects of perceptual maturity which are investigated by these tests. Those children with shunts reflected overall a greater measure of perceptual immaturity than those without shunts on the Bender Gestalt and those with shunts were marginally less successful on the Raven's Matrices. The boys tended to be more perceptually immature than the girls on the Bender whereas the former were marginally more successful on Raven's.

Some researchers have noted a close link between intellectual development and perceptual ability and suggest that an impairment in this area is an expression of low intelligence. An examination of the inter-test correlations in this particular study showed that although there was a clear link between I.Q. and the visuo-motor ability as measured by the Bender-Gestalt the correlation was not nearly as high as might be expected. It was also interesting to observe that when the relationship between I.Q. and degree of handicap was studied the relationship, although significant, was lower than might have been expected.

To some extent, therefore, the observation made by other researchers that although children with average or above-average I.Q.s do better on the Bender Gestalt, those with immature scores may have high or low I.Q.s depending on what other factors are present. It seems necessary therefore to look beyond the variables of I.Q. and degree of overall handicap, even though these factors play a part to the reasons for the under-functioning of spina bifida with respect to visuo-motor performance. It would appear that the hydrocephalus is a factor which needs to be taken into account particularly when the mental function which controls visuo-motor activity is concerned.

The teacher should be fully aware of the strong likelihood that the academic performance of the spina bifida child might, particularly in the early years at school, be affected to some degree by visuo-motor problems. The problem can be either visual or motor or a combination of both — a failure of some mental

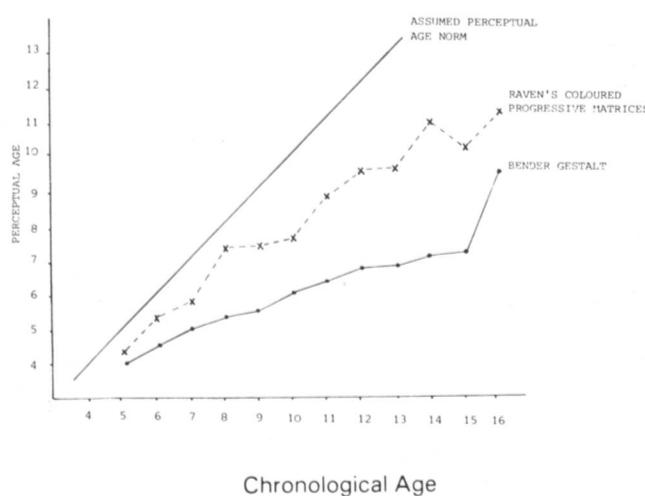


Fig 1. Perceptual test results for spina bifida children

functioning which helps the child to integrate these skills.

Since the main aim of this study was primarily to investigate questions relating to the development of number concepts it is important to ascertain if there is a link between this aspect of cognitive ability and visual-maturity. Several writers have stressed that mathematics and related subjects present particular difficulties to children with poor visual-motor skills. Some emphasise the role of body movement and manipulation of objects in the development of number concepts, examples of which are the basic ways in which time and space are related. Questions the child might ask in this respect are, "Will it take *longer* to walk or run?", "Will I arrive first if I am *faster*? ", "I walk *around* the chair, and then I will crawl *under* the table. Is the table *high* enough?", "I will run a *straight line* first and then a *curve*?".

It needs little imagination to realize that experiences leading to the appreciation by the child of the concepts above are not to any great extent enjoyed practically by many spina bifida infants.

Eye-hand co-ordination is clearly important in the accurate positioning of numerals, in ensuring the legibility of figures in mathematical processes and in the construction of geometrical shapes. It seems natural, therefore, that the more severely handicapped spina bifida child, because of the lack of physical experiences in infancy and some developmental immaturity in both fine and gross movements is likely to have early problems in the acquisition of mathematical and other related skills.

In the light of this knowledge those concerned with the education of such children should actively intervene by providing suitable strategies at all stages of educational development and in all subjects which could possibly be affected by such a perceptual deficit.

Such intervention together with exposure to a normal curriculum and the child's own internal compensation for the deficit has been relatively successful with some of the children on whom the study was based.

**BELOW** is an explanation of some of the terms used in the article:

**1 Visuo-spatial ability** . . . the ability to judge distances, to appreciate terms such as 'nearer than', 'farther than', 'wider', 'narrower', 'lower', 'higher', directionality, left-right discrimination', orientation.

**2 Lateral confusion** . . . reversals in letters and in words problems with left and right, bizarre writing, drawing and spelling.

**3 Organisation of representation** . . . refers to the ability of planning and executing motor movements.

**4 Visuo-motor** . . . the ability to reproduce that which is seen e.g. copying shapes, matching, tracing and sorting.

**5 Distortion** . . . not a faithful and accurate copy of a given shape(s), inaccurate proportions.

**6 Rotation of shape** . . . a faithful reproduction of the orientation of the original drawing.

**7 Integration** . . . the ability to reproduce faithfully the relative positions of the several shapes in the original drawings.

**8 Perseveration** . . . a child with perseveration behaviour continues an activity beyond its correct stopping place e.g. a child may not be able to stop after writing the letter 'a' the three times required, instead the activity is continued until a whole line is filled with "a's".

**Dr Vernon Parfitt, Ash Field School,  
Leicester**

**Dr David Green, Loughborough University**

- An article by the same authors appeared in the last LINK on the subject of the abilities of spina bifida children with regard to number work and mathematics.

\*Parfitt V (1979). The Development of Number Concepts in Children with differing degrees of Spina Bifida and Hydrocephalus. (Unpublished Ph.D. thesis, Loughborough University Library.)

## JOHN GROOMS HOLIDAYS

All facilities specially adapted for wheelchair users  
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**Seaside Hotels:** Llandudno and Minehead. (Bargain Winter Breaks for only £10 per day, incl. VAT)

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**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.

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



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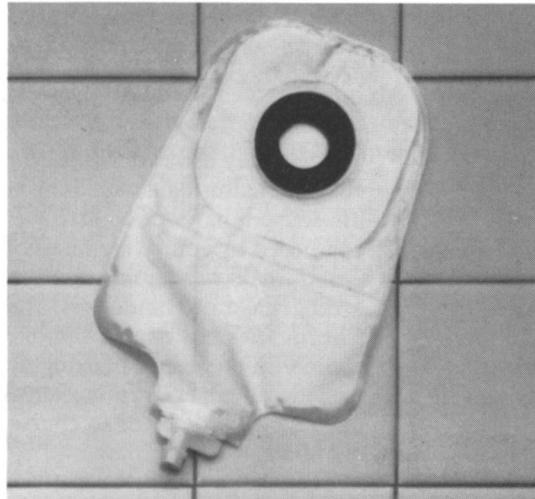
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In fact the more you see of the Lo-Profile<sup>\*</sup> urostomy bag by Hollister, the more you may come to think it deserves a high profile.

### **Request to try the Lo-Profile<sup>\*</sup> urostomy bag by Hollister**

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**ABBOTT**

*IN LINK we often publish information about different kinds of holidays, so we thought it would be a good idea to ring the changes and carry a personal account instead. Here Zem Rodaway, a young member of ASBAH from Haywards Heath in West Sussex, has written about two holidays she enjoyed last year.*

"DURING 1982 I went on a week's pilgrimage to Lourdes with Handicapped Children's Pilgrimage Trust. The majority were aged between seven and 18, although I went with Jet Set II which comprised a slightly older group and most people were in their twenties.

The group consisted of ten disabled people and ten helpers including a doctor, nurse and priest. We had a meeting a few weeks before the pilgrimage, so when we met at Victoria Station we were able to recognise members of our group. We travelled by train to Folkestone, where we took the boat to France. The whole journey took about 24 hours so there was plenty of time to get to know each other.

Once in France we boarded the train for Lourdes, where on arrival we settled into one of the many hotels.

During the week there were many places to see — mainly connected with the story of Bernadette. In one vision Mary told Bernadette to drink at a spring. She had to scrape with her hands before uncovering some water. The spring became stronger and is now channelled into 'the baths'. Although many healing miracles have occurred at Lourdes, Bernadette's message from Mary was that people should go to Lourdes for prayer and procession.

On our visit there were activities every day. There was a Mass and every evening we went down to the Grotto where Bernadette had the visions, for evening prayers.

Everyone was encouraged to take part in all the activities, but no-one was made to do anything they didn't want to. There were several group discussions which were very helpful, and plenty of opportunities to talk to the priest or anyone else about problems.

There were candle-lit processions every night, and to see hundreds of flickering lights was a beautiful sight. On the Thursday the entire

## Zem picks holidays with a purpose

HCPT group (about 4,000 of us) gathered in the Underground Basilica.

In case I am making the pilgrimage sound very 'religious' I should also say we had plenty of fun. Each group spent a day in Gavarnie, a small town in the Pyrenees which was very pretty. There were plenty of sing-songs, time to look around Lourdes and other places connected with Bernadette, and time to go shopping.

One did not have to be a Roman Catholic. Our group was very ecumenical which meant we all learnt from each other, and there was a fantastic atmosphere of fellowship throughout the week."

*ZEM'S second holiday was quite different — a week's Woodwind Workshop at St Mary's College, Twickenham.*

"THE COURSE catered for all standards, and a wide range of ages from teenagers upwards.

Before the holiday we had been given a short list of pieces and had to prepare at least one. In the mornings we split up to go to masterclasses for our particular instrument. During the week everyone had the chance to play at least once.

We studied individual pieces, and picked up tips on fingering, breathing, instrument care, and ensemble playing.

During the afternoons the advanced players formed into chamber groups, while most of the others joined the woodwind or clarinet choir.

Each evening there were free concerts for the workshop participants — although by then some may have had a large enough dose of music! All the woodwind instruments were featured in these concerts, given by some very good professional players.



Zem Rodaway

Thursday's concert was rather different but still very enjoyable — a few hours jazz played by the 'Little Big Band'.

On Friday it was our turn to give a concert, featuring a wide range of music from baroque to jazz composed by course members. The grand finale was an *unrehearsed* arrangement of Handel's Alleluia Chorus for oboe and saxophone choir with orchestral backing provided by the rest of us. This was played by all the 60 or so course members.

The course usually takes place from Monday to Friday of the third week in August, and although there was quite a distance between our hostels and the main part of the college, there were few steps to be negotiated. The only flight was up to the ballroom for the concerts, but there should be plenty of people willing to lift wheelchairs.

Music is, of course, something which the disabled can participate in on equal terms with the able-bodied, and it can certainly keep me interested for hours. I would recommend the course for sparking off a new enthusiasm for, and greater enjoyment from, your instrument."

The address for details of the Lourdes holiday is: HCPT, 119 Westmead Road, Sutton, Surrey; for the music course: Woodwind Workshop, 69 Shakespeare Road, Hanwell, London W7.

● **Shortly before going to press we heard the good news that Zem had been awarded the Duke of Edinburgh Gold Award, and her mother told LINK that Zem recently also passed her driving test! Many congratulations.**

# Fancy that — birds, Stars and talkers all support ASBAH

Appeals staff at ASBAH are now embarking upon an intensive run of innovative fundraising ideas for 1983.

THE YEAR got off to a good start when Ann Gosling and I travelled to Blackpool for the British Homing World Show of the Year. Pigeon fanciers have always proved most generous to ASBAH. Last year the magnificent sum of £12,000 was given to us, as a result of the Show.

Now in view of the substantial sums of money being raised it has been decided by the Shows Committee that another charity should also benefit and the British Heart Foundation has been selected. Needless to say, were were a little sad not to continue to be the sole beneficiary, but fate was very kind and thanks to the superb organisation of Major Len Lewis and his Committee, 1983 proved to be a bumper year with approximately 14,000 fanciers attending and a record number of birds in the Gift Auction.

We are therefore quite hopeful that the contribution may be equivalent to that presented to ASBAH in 1982, with the same going to our new 'partner in benefit'.

Back in London, Barry Mishon was working up to a most unusual event at The Lyceum Theatre on Sunday, 6 March. It was The Stage Door Canteen, a re-creation of the war time extravaganzas when the leading stars of the day turned out to entertain the troops and act as bartenders and waitresses. Some of the stars who supported the original canteens were due to be in attendance again, together with today's personalities. The aim was to provide an opportunity for people to relive past experiences and for the younger generation to see what it was all about.

The front of The Lyceum was to be sand-bagged and a Bofor gun and search light were to add to the atmosphere, as would air raid sirens and The Herb Miller Orchestra, playing the music made popular by Herb's brother, Glenn.

In the middle of April, Mr. Ian Morrison will be promoting the second *Chatathon* to find The Conversationalist of the Year, 1983, following the success of last year's event. The venue for this year's twelve-hour conversational marathon is the Inter-Continental Hotel, London and early signs would indicate that we may achieve our target of 100 enthusiastic talkers.

Tony Deeson, ASBAH's public relations consultant, and I will once again be participating, but because twelve hours seemed a bit short to us last year, we will be attempting to establish a "distance" record by talking from the start of the event at 10.00 a.m. on Saturday, April 16, until the contest ends on Sunday evening.



Talking of talking, ASBAH's telephone sales department seems to be doing this to excellent effect, having raised a staggering sum of in excess of £125,000 gross, since the department's inception last June. The photograph on this page adds faces to the voices. Sitting in the centre of the group is Mrs. Sue Owen, our Sales Manager; the other personalities in the picture are: left (standing) — Richard Poole, below him Brian Cornibert, Pauline Ashcroft, in the foreground Lindsey Knight and on the other side of Sue, Anna Distefano, Mark Brett with Tim Haydon standing behind him.

Judy Kay, Director of Appeals

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Please send remittance with your advert.

Adverts for the next LINK (May/June) should be in by April 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

## HOLIDAY ACCOMMODATION

**CAMBER SANDS.** Well-equipped and adapted chalet (sleeps 6). Bookings taken by Mrs N. Kerswill, 28 Ilmington Rd, Kenton, Harrow, HA3 0NH. Tel: 01-907 8526 (2-7 pm).

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## ASBAH booklets, etc . . .

*Your Child with Spina Bifida*, by J. Lorber, MD, FRCP..... 35p

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*Children with Spina Bifida at School*, Ed. P. Henderson, CB, MD, DPH..... 50p

*Sex and Spina Bifida* by Bill Stewart.... awaiting reprints

*The Handwriting of Spina Bifida Children*, by Joan Cambridge and Elizabeth M. Anderson..... £1

*The Nursery Years*, by Simon Haskell & Margaret Paull..... 35p

*Little Joe (A Grandmother's story)* by W. Foster..... 50p

Information leaflets..... 100 for £4.00

Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free from national office. Translations into Bengali, Gujarati, Hindu, Punjabi and Urdu. Welsh language sheets are now ready too. All available from ASBAH. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

### Scottish Spina Bifida Association Booklets

*Growing up with Spina Bifida*..... 35p

*The Spina Bifida Baby*..... 35p

both by O. R. Nettles, McSP, ONC.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

## FUND RAISING AND PUBLICITY MATERIAL

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**For local publicity 15 x 10 in.**..... 10 for 40p

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**Plastic Lapel Badges**..... 8p each

All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins

16 mm Colour/Sound..... £4 Hire

The Appeals Dept. carries a range of fund-raising and publicity items, i.e. posters, pens, key rings, games. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

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