



Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

July/Aug 82



See page 4

In this bumper 28-page LINK: National trial to test preconceptual vitamins: Research news: All about Prescription Charges: Teenagers in hospital—informality is the key: Spina bifida in Spain: Scouting—a challenge for *all*: Disabled people set up British Council

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Association for Spina Bifida
and Hydrocephalus/ASBAH

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Vitamin supplementation

A LARGE Multicentre trial has been announced (see page 8) to find out once and for all whether vitamin and folate pills taken before conception really can prevent the birth of spina bifida babies.

After the results of Prof. Smithells' and Prof. Laurence's research (LINK Jan/Feb 1982 and March/April 1982) many people will already feel that the case has been proved. But general medical opinion is that the results are not conclusive and that it is vital to carry out an appropriate study if we are to know whether vitamin supplementation is worthwhile and whether it should be made available on a national scale, where needed, to prevent the birth of a great many babies with neural tube defects.

The new trial, being conducted under the auspices of the highly-respected Medical Research Council, is the subject of debate at the moment because one quarter of the women chosen to take part will, without knowing it, be taking a dummy tablet—one containing only iron and calcium. Another group will get a tablet containing only vitamins, another only folates, and a fourth group will take Pregnavite Forte F which comprises vitamins and folates.

Neither the consulting doctors nor the women in the trial will know which of the four tablets are being taken until after the trial is over. This is important to avoid introducing bias into the study so that the results can be completely reliable.

ASBAH has decided to give its support to the trial, but only after a great deal of discussion. When the trial was first mooted, the initial reaction of many people within ASBAH was on no account could they be behind it.

Duncan Forrest, Chairman of the Medical Committee of ASBAH sums it up: "We felt at first that we couldn't back something like this where some of the women would, in effect, be getting nothing, and could be being denied life-giving vitamins. But we do not know that vitamin supplementation works. It could be a false alarm. We must know as soon as possible. It was felt that it is ASBAH's duty to attempt to prevent spina bifida."

Mr Forrest also points out that the trial has to take place now or never. If there is further delay then the population would come to believe implicitly in pre-conceptual vitamins and no-one would be prepared to take part.

ASBAH has decided to support the trial. This doesn't mean, however, that it will seek to influence individual parents.

It is a very difficult decision for a woman to make—often at an extremely emotional time, after the loss of one baby. Once parents have all the facts it is up to them to make up their own minds.

ASBAH, appreciating the difficulty that many parents will have in deciding what to do, is willing to listen and answer questions, if anyone feels they would like to get in touch. No doubt, local associations will be discussing this important subject.

General factsheets, produced by ASBAH, will be distributed to doctors, clinics, medical centres etc.

The new trial will also give research workers a chance to study the longer term effects of taking vitamins and folates for some women, and for their children. So far there is no evidence at all to suggest that there is any harm in taking either in reasonable doses.

The future may indeed be a much brighter one for women if the possibility of producing a handicapped baby can be significantly reduced. In the short-term there will be much heart-searching among the present population of 'high risk' women as they make up their own minds whether or not they will participate in this new national trial.

The 1/20 chance of a woman having a second spina bifida baby will not be increased if she joins the trial. She will have the benefit of the best prenatal facilities available and the satisfaction of knowing that she is playing an important part in a crucial piece of research which could benefit parents of the future.

Editor

Government casts a doubtful eye on call for anti-discrimination law

A RECOMMENDATION for anti-discrimination legislation in favour of disabled people has failed to impress the Government.

The recommendation is contained in the recent Report of CORAD, the Committee on Restrictions Against Disabled People which was set up in January 1979 by the then Government to "consider the architectural and social barriers which may result in discrimination against disabled people . . ."

Commenting on the Report, the Minister for the Disabled Mr Hugh Rossi said:

"The Government has been considering the Report's recommendation that there should be anti-discrimination legislation. I know that some disabled people suffer unnecessary restrictions but much has been done by education and publicity to improve the position.

"It seems better to build on this,

than to legislate for positive discrimination as a right. The loss of goodwill might outweigh any advantage gained, particularly for the less able and most severely handicapped.

"Before considering the introduction of such far reaching legislation we would need to have good evidence that there were significant breaches of human rights and I do not think the Report provides this evidence.

"There are some very telling anecdotes but without any attempt to validate or quantify them it would not be right to base major policy changes on them. The Committee's Questionnaire elicited a very low response which suggests that such cases, disturbing as they are, are the exception.

"I think it is a pity that the Report did not consider in more detail the practical difficulties of implementing legislation. The US experience has convinced many

commentators that legislation in this area does not work: it is either prohibitively costly and cumbersome or has so many loopholes that it becomes worthless.

"I am not therefore convinced by this part of the Report. It is now up to the disability organisations and the community as a whole to make known their views on how to improve the participation and integration of disabled people."

CORAD's work to improve access for disabled people came in for a good deal of praise from Mr Rossi. He said the Government is looking into the best way of setting up a national access committee, as recommended by CORAD.

**Report of the Committee on Restrictions Against Disabled People. £5.35 from DHSS Publications Unit, PO Box 21, Stanmore, Middlesex HA7 1AY.*

Free fishing

A TROUT fishing day for disabled anglers is being organised, for the second year in succession, by the Amey Roadstone Corporation.

It will take place on Stoneacres Lake, Linch Hill Fisheries, Stanton Harcourt, Nr Eynsham, Oxfordshire on Wednesday August 18.

Registered disabled anglers or members of disabled angling clubs are invited to attend as guests of the company. Fishing will be from 9 am to sunset.

The bag limit will be two fish. Anglers may continue fishing but will be asked to pay for fish in excess of the bag limit. Boats will be available free on a 'first come first served' basis.

The day will be divided into three hourly sessions so that everyone may have a chance to fish from a boat. Life support belts will be available and must be worn.

A buffet lunch and refreshments will be provided free of charge, and it is hoped various organisations will offer prizes.

Special toilet facilities for the disabled are available.

This year's day follows the success of the trout fishing event organised by ARC for 1981.

For details and forms contact: The Fisheries Office, ARC Development Dept., Besselsleigh Road, Lower Wootton, Nr Abingdon, Oxford OX13 6EF. Tel: 0865 730851.

FRONT COVER

TRAIN driver, Bill Leonard, with 14-year-old Simon Chisnall of Boxted, Essex, taking the controls—while the train was in the station!

Simon, who has spina bifida, wrote to British Rail Chairman, Sir Peter Parker about job prospects, and the BR Chief arranged a tour of Liverpool Street station, and a ride in the cab of the London to Norwich Inter City Express train.

British Rail have also been helpful in talking to Simon about job prospects and explaining the exams he needs to pass. Simon would like to do clerical work connected with the maintenance of locomotives.

Photo: Essex County Standard

DLF looks at clothing problems

CLOTHING and dressing problems for people, of all ages, whose disability includes scoliosis are 'coming under the microscope' at the Disabled Living Foundation

Can you help? If you have clothing or dressing problems to which you may or may not have found solutions, please contact DLF Clothing Adviser, Mrs Peggy Turnbull, Disabled Living Foundation, 346 Kensington High Street, London W14 8NS.

New centre

AN ADVENTURE centre, costing £800,000 is to be built for disabled people at Low Craneclough on the banks of Kielder Water in Northumberland.

New magazine

HANDICAPPED Living is a new monthly magazine for disabled people and their families and friends and is available at bookstalls all over the country.

Spina Bifida prevention—a national trial

Vitamin theory to be put to the test

A LARGE scale research trial to find out conclusively whether vitamin and folate pills taken before conception are effective in the prevention of spina bifida, is to get underway soon, probably in the Autumn.

The trial to be conducted from 19 centres in the United Kingdom, and in Israel and Australia, will involve between 2,000 and 5,000 'high risk' women wishing to have babies.

This new move, which is being backed by the Medical Research Council and the Department of Health, comes as a result of the encouraging results of the trials led by Prof. R W Smithells and Prof. K M Laurence (both reported in earlier LINKS).

Dr Nick Wald, co-ordinator of the trial, said that the tests that had been conducted so far into vitamin supplementation looked, on the face of it, to be very hopeful. There had been a much reduced incidence of spina bifida babies born to those mothers who had taken the vitamin and folate supplementations.

"But there are two possible explanations for this" he said. "One is that vitamin supplementation works; and the second is that inadvertently the mothers chosen for the trials were at a lower risk of having spina bifida babies than those who didn't take part".

Before the Department of Health and the medical profession are prepared to back vitamin supplementation wholeheartedly, they wish to have a larger-scale, more scientific trial, that would prove the case once and for all. The new research would also show whether it was the vitamins, or the folates that were effective or whether a combination of both was desirable.

For the purposes of this trial women considered to be 'high risk' are those who have lost a baby with spina bifida or another neural tube defect, or mothers who already have a spina bifida child, and are considering a further pregnancy.

Because of the necessity of conducting a large scale survey, it is hoped that as many high-risk women as possible will agree to participate. But it is emphasised that participation in the trial will be entirely voluntary. Parents, when they know all the facts, will be asked to make up their own minds, say the Medical Research Council.

Those taking part will be divided into four groups. One will take a tablet containing only iron and calcium (a placebo), another group will take 'a vitamin cocktail; another will be given Pregnavite Forte F containing vitamins and folates (as used in the Smithell's trial), and the fourth group will take a tablet containing only folates (as used by Prof. Laurence). The women will not be told which kind of tablet they have been prescribed.

The tablets will only need to be taken once a

day—much easier than the three-tablets-a-day regime of previous trials.

The organiser will make contact with the women in a variety of ways—through doctors, clinics, medical centres. After an initial interview, participants will be asked to attend the centre every three months for 'monitoring', probably by the health visitor or midwife, or social worker. A urine sample will be taken to ascertain that the tablets have been taken regularly.

The Medical Research Council points out that all the participants whichever part of the country they live in, will get the benefits of full ante-natal care, and screening, and if it is shown that they are carrying an abnormal fetus they can choose to have the pregnancy terminated.

The trial could take as long as five years. If early results are conclusive, however, then it will be stopped. If the case for vitamins or folates is proved, then further research can be carried out to ascertain why certain women need the supplementation. In this way it may not prove necessary to dispense expensive vitamin pills nationally to all women, but only to those in special categories.

The centres taking part in the trial will be announced later.

See also *Opinion* page 3.

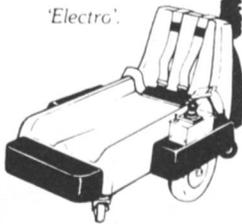
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The Welsh invite you to the Albert Hall

THE SOUTH Wales Association have undertaken a mammoth task in fund-raising by organising a concert to take place in the Royal Albert Hall, London, on February 12 1983.

Taking part will be one of Wales' premier choirs, the Treorchy Male Choir, supported by Josephine Jones, a soprano from Merthyr and Huw Tregelles Williams, who is a recital organist and Music Producer with BBC Wales. The concert will be compered by Alun Williams, BBC Wales broadcaster, a popular personality who is familiar to Albert Hall audiences.

This is a unique event in that as far as it is known this is the first time that the Royal Albert Hall has played host to a single choir performing for charity, as distinct from organised mass festivals. Considerable interest has already been shown and orders for tickets have been accepted since March.

The Treorchy Male Choir are noted throughout the country for their charity work and have already given concerts for ASBAH Associations in the cities of Stoke, Sheffield and Coventry. They have



THE START of many good holidays . . . this super caravan, with full facilities, is now in the proud possession of Hull and District Association. Chairman, Philip Brown (second from right) is pictured receiving the keys from Martin Bellamy, Chairman of the Hull and Humberside Round Table who worked so hard during the year to raise the money. They held a whole variety of fundraising events including a motor cycle scramble and boxing matches. The caravan is situated on a very select site at Far Grange, Skipsea.

appeared many times on both BBC and ITV and their records are frequently played on Radio.

Indications are that this will be a successful evening and everyone wishing to attend can obtain further details and a ticket order form from the South Wales Association Secretary, Mrs Brenda Sharp, 38 Redbrink Crescent, Barry Island, South Glam. Tel. Barry 735714. If you do make enquiries please enclose a stamped addressed envelope, and do not leave it too late.

Why not organise a weekend in London?

Towards independence . . .

PONTEFRAC T ASBAH organised a special Saturday meeting for some of its teenage members earlier this year. Margaret Pearson, (ASBAH Fieldworker), Mary Barton (Disabled Living Adviser based at Five Oaks) and Jill Vernon, from National Office also attended.

Members cooked their own lunch (and washed up!), tried to improve their wheelchair proficiency and had a chance to discuss individual problems, and talk about what they wanted from LIFT.

IYDP medallion for Mrs Thursby

MRS SHEILA Thursby, the Honorary Treasurer of the South Wales Association, has been awarded a special medallion by the South Glamorgan County Council.

Mrs Thursby and 40 other individuals were selected for their outstanding contribution in working with and for disabled people during I.Y.D.P.

The South Wales Association expressed delight at its recent annual meeting that Mrs Thursby's work had been recognised and honoured in this way. Mrs Thursby has been the Honorary Treasurer of the South Wales Association since it was founded in 1965.



Rosemary Hawkes of Palmers Green, North London with the Mini presented to her under the Motability Scheme by TV star Leonard Rossiter, at a special event in London in May. The event was part of a day of activity in aid of Motability.

LINK reports on one of the research projects being supported by ASBAH. In future issues there will be news of other ASBAH backed research.

MR Z A RALIS, MD, FCCS of the Orthopaedic Research Laboratories, Welsh National School of Medicine in Cardiff has discovered a new factor responsible for the deformation of limbs and feet of children with spina bifida and paralysis.

How pressure in the womb can result in deformed limbs and feet

WHEN A baby is born with spina bifida, his legs are frequently paralysed and his hips, knees or feet are often in a bizarre shape or position. During the last 25 years it has been the belief that most of the spina bifida deformities were caused entirely by the paralysis, because those muscles which were paralysed and so not working, would be overstretched by their normally working opponents and a deformity of some sort would result.

Many operations based on this premise were designed to improve the shape and function of the paralysed limbs, but there was a large group of children in which the operations did not work or worked for a short time, and where the deformities could not be explained by the paralysis only.

Mr Z A Ralis, from the Orthopaedic Research Laboratories in Cardiff, whose project is now supported by ASBAH, started to examine in detail the muscles and nerves from spina bifida children to try and find an answer to this problem. After dissection and microscopical examination of

hundreds of samples and after studying the deformed limbs from rat foetuses with spina bifida, several new facts came to light:

First, it became obvious that in those treatment resistant and rigid deformities the type of paralysis did not match the state and microscopical structure of the muscles and, therefore, the deformity could not have been produced by the paralysis itself.

Secondly, in those rat foetuses with spina bifida whose limbs were completely paralysed, the motionless limbs were deformed in such a way that they formed an exact cast of the uterine corner in which the foetus had been developing.

These observations gave Mr Ralis the idea that since a "dead", motionless limb cannot escape from, or kick away any pressure imposed on it inside the womb (in the way that a normal developing limb could), it would, therefore, allow any such mechanical pressure acting on it to mould it into a bizarre shape. This pressure accounts for the shape of the deformations and is also the reason why operations based on calculations that muscles alone are responsible for the change in shape are not successful.

During further dissections, a third piece of evidence was found in the direct signs of such mechanical pressure, either on skin of the toes or over the joints: the presence of this long-lasting direct pressure was also verified under the microscope.

And so, a new important factor has been discovered—mechanical intra-uterine pressure—which, together with paralysis, is responsible for these bizarre "paralytic-pressure" deformities, which will, of course, require a different treatment.

MR RALIS has also been examining the question of why children with spina bifida suffer so much more often with fractures than normal children.

A fresh insight into bone weakness

DOCTORS treating children with spina bifida noticed a long time ago that those with paralysis frequently sustained fractures of their bones which, obviously, added to their existing handicaps.

Until recently this was thought to be due to the fact that the bones of some of these children appear thinner than normal on X-ray, but even those bones which do not show any apparent thinning are still more fragile than those of normal children.

Mr Ralis recently employed two new micro- and ultramicroscopical techniques in the study of a large number of bone samples from these children. With the use of these techniques it is possible to see changes which occur "inside" the bone tissue and in mineral crystals.

Mr Ralis was able to describe—for the first time—that the bones from paralysed limbs contain large areas in which the bone mineral (this is what makes our bones hard and firm) did not develop normally and completely. Such bones with deficient mineralization are obviously weaker than they should be, and this was the answer to the problem.

By a lucky coincidence Mr Ralis also found a possibly efficient remedy which could improve the

quality and mechanical soundness of these fragile bones. From his previous work he knew that deformities in paralysed limbs in spina bifida children were produced in two different ways—either by paralysis of muscles only—or by a direct mechanical pressure which was deforming the paralysed limb inside the womb.

When he compared results of screening of his bone samples in these two different groups, he found that in the latter group bones were better preserved and less damaged, which indicated that the mechanical pressure inside the womb present in this group, which was unfortunately deforming the limb or foot into a malformed shape, had, on the other hand, a positively protective influence on the paralysed bones and slowed down their deterioration.

Mr Ralis is now recommending the frequent addition of therapeutic pressure on these bones into the physiotherapy programme for these babies to help their handicapped bones to stay in a better shape.



ASBAH's research work was featured as part of the exhibition staged in London earlier this year by the Associated Medical Research Charities of which ASBAH is a member. The photograph, taken at the exhibition, shows the Duke of Gloucester talking to Miss Moyna Gilbertson, ASBAH's Chief Executive Officer, and (centre) Beverley Holland, the Information Officer.

Photo: Keystone Press

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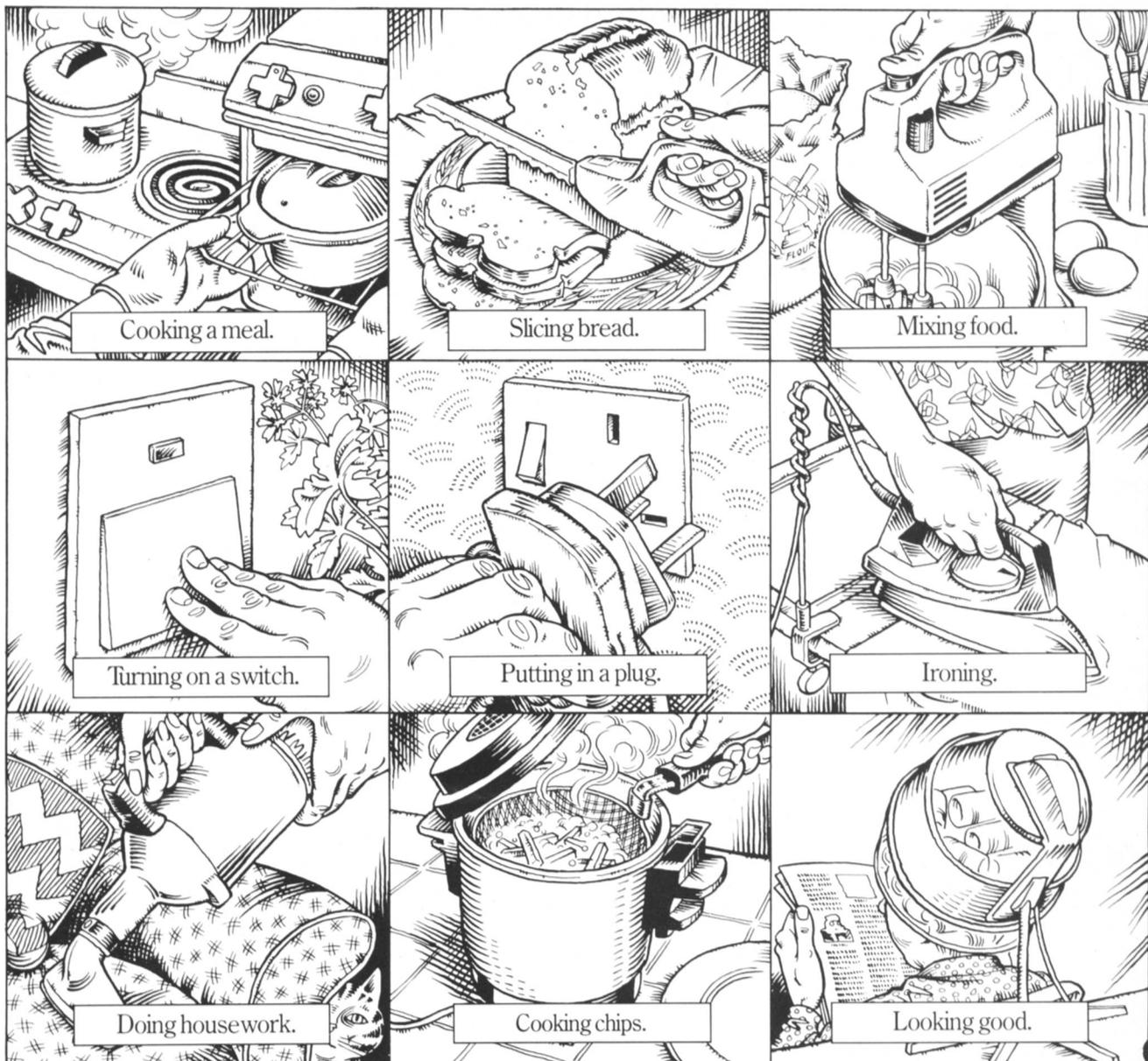
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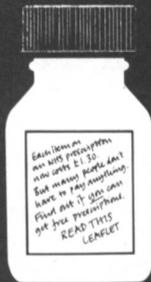
The leaflet also gives details of brailled controls that can be fitted to

certain electrical appliances. And specially designed attachments for plugs and switches which afford easier handling.

The leaflet is free, from your Electricity Board shop. Or you can write for a copy to the Electricity Council, Information Centre, 30 Millbank, London SW1P 4RD.

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The Electricity Council, England and Wales.





PRESCRIPTION charges went up to £1.30 per item in April this year, so readers might like to be reminded about the various categories enabling people to claim exemption.

Who is automatically exempt?

* All children under the age of 16 and all adults over retirement age (60 for women and 65 for men) can get free prescriptions, without needing an exemption certificate, if they fill in the declaration on the back of the prescription form.

Who can get an exemption certificate?

- * Pregnant women and mothers who have had a baby within the last 12 months.
- * Disabled war or service pensioners.
- * People getting Family Income Supplement or Supplementary Benefit.
- * People with a low income. Young people over the age of 16 can claim free prescriptions *on their own income* even if they are still at school or college.
- * People with a urinary diversion, ileostomy or colostomy.
- * People suffering from various disorders requiring continuous medication, such as diabetes.
- * People needing medication to control epilepsy.
- * People with a continuing physical disability, which prevents them from leaving home without the help of another person.

For further details and claim forms, ask for leaflet P11 "NHS Prescriptions—how to get them free" from any post office or social security office.

New Disabled Living Adviser

ASBAH welcomes Rosie Horsfall, who has recently joined us as an additional Disabled Living Adviser. Rosie comes from a background of nursing and social work. She will be working with Jill Vernon in giving information and advice on personal care.

Association of Contenance Advisers

IN APRIL, Jill and Rosie went to Newcastle to attend a Conference of this new Association of Contenance Advisers which was set up in September last year. Membership is open to those who have a special interest in the topic and who work in an advisory capacity.

The Association aims to educate and inform the public, professionals in the field, and the Health Authorities on existing

services and to press for improvements. Research findings will be collated and the Association will act as a resource centre, gathering and disseminating information.

Toys for mentally handicapped people

LEEDS ACTIVE group are now producing a range of exciting wooden toys, including the "Roller Tower", "Tumbling Clown", "Wobbling Man" and "Rachel's Rattle"!

This group are also converting a small tricycle so that it can be propelled by hand, and will also modify a suitable tricycle selected by the child.

For a catalogue including further details send a P.O. or cheque for 45p (payable to ACTIVITY Toy Trust) to: Leeds and District Active, 3 Roxholme Terrace, Leeds LS7 4JH.

MARTIN Sharkey one of the teenagers at the Pontefract Saturday meeting is learning to use a wooden transfer board to help him get into the car on his own, with guidance from Mary Barton.

A transfer board is a very simple piece of smoothwood, which can bridge the gap between your wheelchair and a bed or another seat, so that you can feel confident to transfer without being afraid of falling.

Boards can be made locally, or can be bought from the following firm:

Classwood Ltd., 41 Oldbury Road, Tewkesbury, Glos. Tel: (0684) 294270.

12' x 18", 12' x 30", or other sizes made to order.

Photo: Yorkshire Weekly Newspaper Group



ASBAH Mobility Service

HERE is a correction to an article in May/June LINK.

Mrs Leonie Holgate ASBAH's Mobility Adviser will be at Banstead Place between 9 a.m. and 3.30 p.m. every **THURSDAY**.

The full address is Mrs Leonie Holgate, ASBAH Mobility Adviser, Banstead Place, Park Road, Banstead, Surrey. Tel. Burgh Heath 56222.

Contact Leonie if you would like a leaflet on the new Banstead Place Mobility Centre.

Information compiled by Jill Vernon and Rosie Horsfall, Disabled Living Advisers.

LINK'S SPECIAL Supplement 'Lives in Question' has been in demand following its publication with the March/April issue. It has provoked much interest, and its views and opinions are being studied by the Ethical Committee of the British Medical Association. Here are two views from LINK readers:

I AM WRITING about the LINK Special Supplement *Lives in Question* which discusses the current controversy over the treatment of newborn spina bifida babies.

I am 27, and confined to a wheelchair due to spina bifida. This subject has been of great interest to me for some time, and I have had letters printed in "The Guardian" and "The Times", defending the equal right to life of handicapped people.

I had looked forward to reading a balance of different views in your supplement, and it was thus with a sense of incredulity that I discovered that *there is nothing in it by anyone with spina bifida*.

I wonder how you would defend your decision not to include anything by the people most intimately involved? Of course, these decisions cannot be made by a newborn baby, but how can parents make a realistic choice when presented with predictions such as those of Professor Lorber?

Did you really think people with spina bifida would read his opinion that we are "dwarf, clumsy, often very fat and have squints" and feel it was a fair and accurate self-portrait? No wonder some parents choose death for their baby when faced with such an overwhelmingly dismal picture of their future possibilities.

It is not enough to say that this is a description only of the worst cases of both spina bifida and hydrocephalus, because later in his article, Professor Lorber says that severe paralysis of the legs alone is a sufficient contra-indication to active treatment, provided the parents agree. This, of course, would

Living proof of a full life

include those with a similar potential degree of disability to mine.

Naturally I was pleased to read refutations of this view by Professor Zachary and Ian Kennedy. Nevertheless, I think the strongest refutation of all would have been the view of someone disabled enough to be categorised by Professor Lorber as likely to have an unacceptable quality of life, who is living proof to the contrary.

I have been married for seven years, and have a University degree. I have travelled widely in Europe, the United States and the Soviet Union, and have many plans for the future, as do others with spina bifida. I am very happy to be alive, and for this reason I will not sit quietly by while you allow people like me to be described as clumsy fat dwarfs by those who choose whether we live or die, and deny us the right to of reply.

MRS ALISON DAVIS
Colchester, Essex.

EDITOR'S Note: LINK is certainly not denying you the right of reply, and we hope very much that other readers with spina bifida will be stirred into action and send in their opinion. We did not perversely exclude anyone with spina bifida writing in the Supplement, but it was primarily a platform for the medical profession and parents to give their views, based on experience of the terrible dilemmas and choices that face them at the birth, or the expected birth of a baby with spina bifida. At that time, it is their decision and therefore the supplement concentrates on this aspect.

For every bad time there's a good one

I WAS deeply concerned to read the article 'In some cases it would have been better had the baby died' in the recent LINK Supplement *Lives in Question*.

We are a very similar family unit, one older daughter, one ten-year-old, equally-loved spina bifida daughter who incidentally weighs almost eight stone!

The mother in the article listed so many negative things; please won't someone—health visitor, social worker, anyone—tell her

'Yes, you *can* go to the shops when its crowded.

There is nothing like a wheelchair for melting crowds away! Oh, yes you *can* go on holiday with your handicapped child. Not all beaches have steps.

We have gone on holiday self-catering for years and no-one could have been kinder than the property owners to tell us of easy ramps and access to beaches and which 'loos' have narrow doors etc. in the town.

'Yes, wheelchairs do have to be lifted in and out of a car boot and they are heavy (manufacturers please note). Pushing is hard, but roads like life, are not all uphill all the way . . .'

Friends, we find, take their cue from you, the parents and family. We share our stories, with our

daughter Helen's permission, of burst catheter bags and water samples which are as reluctant to come as water in the desert!

I'm sorry the daughter Joanne in the article gets depressed. Everyone has some handicap and spina bifidas have more than most and it is a strain on the family, but it's a strain on them, too, more so if they feel they are affecting the whole family life, and this is not fair on them.

We told our daughter, Helen, we don't know why she has spina bifida and it isn't easy, but the bigger the step forward the greater the achievement and the joy.

Of course, no-one can imagine the problems a handicapped child will bring. Ten years ago we couldn't either, but for every bad time there is a good one, for every rough night the next might be better.

We try to make the most of our 'special' person, whilst she is with us. We certainly have never felt that 'it would have been better had the baby died'.

MRS S MAYNARD
Woking, Surrey.

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Eric Prichard Ward is a mixed ward of able-bodied and handicapped adolescent patients. Shirley Alywin, SRN, RSCN, ward sister of the adolescent unit at the Westminster Children's Hospital, describes how an informal approach succeeds in integration.

TEENAGE is a stage of growing to maturity, when behaviour is more difficult to define than in any other stage in life. Rapid development takes place—teenagers are frequently moody, fall in and out of love and have many fears and longings.

Alienation from parents prevails, and the adolescent relies heavily upon the peer group, the use of hostility, provocative behaviour and questioning of traditional values. It may manifest itself also in relationships to authority figures.

The adolescent experiences loneliness and depression resulting in much self-preoccupation—particularly the handicapped adolescent who is trying to come to terms with his own body image. He is preoccupied about physical changes and having a body that is different from others.

On Eric Prichard ward at the Westminster Children's Hospital, the adolescent patient is included in the routine planning of the day. It is an eight-bedded unit adapted to help the adolescent; a mixed ward of handicapped and able-bodied patients—the main handicaps being spina bifida and hydrocephalus.

The aim is to bring in able-bodied adolescents to meet staff and patients before expected admission, because these youngsters (including some parents) can become rather upset when faced with handicapped peers for the first time.

Therefore, there is an informal approach to patients, and not too

many rigid rules or regulations. The emphasis is on group activity and all grades of staff participate. The main aim is to integrate able-bodied young people from the community, to encourage peer relationships and to teach total independence where possible.

The idea of a PHAB club (physically Handicapped and Able-Bodied) within a hospital came originally from a patient. This unit has a junior club and a senior club now in existence. The idea is that group members get together on equal terms, usually once a week, to share common interests. Of course, these interests have to be within the physical limits of the handicapped, but it is surprising just how varied they can be.

Voluntary workers are invited in to help. For example, the patients helped a group of art students paint a jungle scene mural. This project was such a tremendous success that they have been asked to help with an underwater scene in a shower room which is being adapted for the handicapped.

Films are shown once a week, and older patients are encouraged to help with setting them up. Sometimes the films are shown on the ward.

Photographs are taken with the patient's permission throughout their stay, recording various activities and hospital care—a useful way in which to demonstrate all aspects of hospital life to patients on admission.

A games room is available for patients and school friends to use—a punch ball is quite useful for getting rid of aggression!

Evening classes in arts and crafts are held every Tuesday evening and various members of staff are willing to share their talents. Ward parties are organised for patients' birthday celebrations and for when staff are about to leave the ward. It is the adolescents' way of being able to say "thank you".

Teenagers enjoy being able to cook and prepare food and snacks for themselves. Diet preferences are arranged for, and a menu choice is being introduced.

Hospital pro approach o to teenage



There is an informal approach to patients and no rigid rules or regulations.

Group discussion

The patient and his family should always be included in conferences with the medical and nursing team to discuss plans for treatment. This team also includes the hospital social worker, a school teacher, physiotherapist and occupational therapist. James Kuykendall, a child life adolescent specialist from America, is with this unit for a year. He counsels the adolescents and parents, and in some cases follows up the patient's progress in the home. The psychiatric team provides an

ives informal can be key integration



ients, and not too many rigid rules

opportunity for group therapy and individual help to patients and their families; it also gives guidelines to help nurses look after their patients.

One nurse is assigned to care for a patient wherever possible, and ideally she should not be too close to adolescence herself. She should be a mature, consistent, yet flexible individual, who has an understanding of his or her own behaviour.

Preparation for learners is by a series of lectures given by the author in the Wolfson School of

• This article is reproduced with the permission of 'Nursing Mirror'.

Nursing before allocation to the ward, and by ward teaching. Provision needs to be made for consistency in relationships to key people throughout the stay in hospital, since it is a period of consolidation of acceptance and coming to grips with feelings.

The adolescent girl reacts to illness by showing concern for appearance, giving attention to the whole body. The adolescent boy shows concern about virility and prowess, and how mutilation of the body will affect his abilities. Patients are encouraged to ask questions, and the nurse must reassure them that their questions and her conversation is confidential.

Intellectual talk can be a useful way to start a relationship. However, one has to be wary of being drawn in on the anger towards the family from the adolescent—empathising with difficulties and infatuations but avoiding identifying (ie, allowing oneself to take on the adolescent's hostilities and yearnings).

The adolescent is conscious about sex, particularly the handicapped teenager who can be confused about relationships with the opposite sex. This can be due to a lack of knowledge or worries over wearing appliances. At this stage in life the concern felt may manifest itself in the patient not caring for himself as before, and seemingly allowing appliances to leak and not changing them when necessary.

A trusting atmosphere may lead to sex education opportunities. The staff should be receptive to questions and be informative. Leaflets are on display in the day room, but the subject material is not imposed on anyone. Genetic counselling is arranged if the patient is concerned about genetic factors in his disease.

The staff must have a fair attitude towards individual differences in interests and abilities, and not force every child to fit into a narrow mould. Praise must be given when it is due—the teenager deserves credit for facing up to his illness.

In conclusion I would like to quote a patient who gave a talk to

students about his illness: "Although I am handicapped and confined to a wheelchair, I am no different from other children".

Acknowledgements

To Miss M Dunne, senior nursing officer, Westminster Children's Hospital.

LIFT hopes for more local groups

LIFT—the organisation for young people with spina bifida and hydrocephalus—hopes to establish more local groups.

Spearheading this effort, is Paul Cooper who brings to the job of LIFT organiser a variety of different talents, including experience gained working with a young volunteer organisation, and as a care assistant working with mentally handicapped adults.

Paul, who went to Newcastle University, takes over from Sue Jenvey who left recently to have a baby.

Paul has recently been involved with forming a new group in Essex, and would be glad to hear from young people interested in joining LIFT and from those who would like to get a group going locally. He can be contacted at ASBAH National Office.

Transport guide

DOOR TO DOOR is a comprehensive guide giving information about transport facilities and services for disabled people on all forms of public transport by road, sea and air. It also covers more specialised forms of transport for disabled people and gives details about buying and running a car and entitlement to aids and financial benefits.

Copies of the guide are available free from ASBAH. Please send a 10" x 7" self addressed envelope with 20p stamps to Beverley Holland at National Office.

Pictures wanted

GOOD black and white photographs are urgently needed by ASBAH for leaflets, LINK, exhibitions. Can you help? If so please contact Beverley Holland at National Office.



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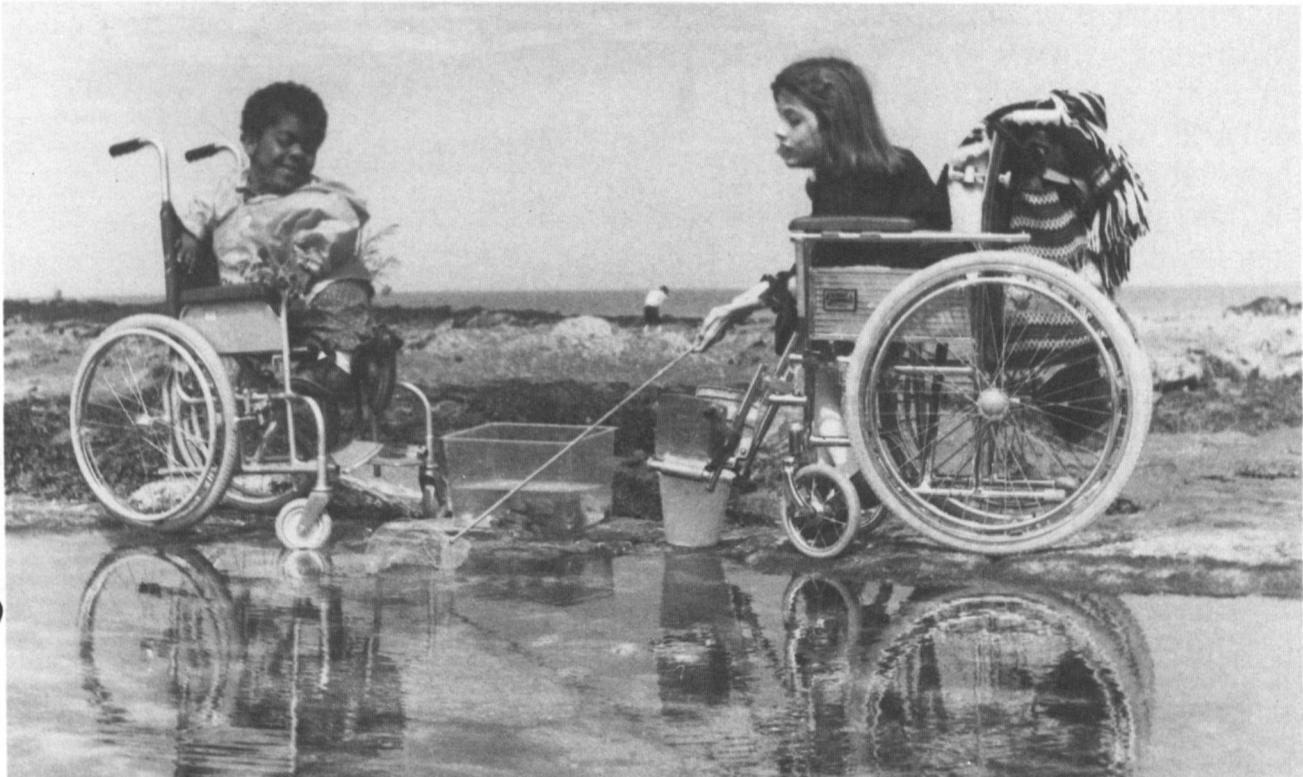
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At the edge of the tide . . . from "Out of Doors . . ." (see below)

Out of Doors with Handicapped People

by Mike Cotton

THE TITLE of this publication does not do justice to the immense variety and interest packed into the pages. Written by Mike Cotton who established the first field studies centre for handicapped people at Churchtown Farm, the book shows young people, whether handicapped or not, how to enjoy their environment to the full, how to make the most of a walk through a park, a castle visit, a stay at the coast.

It covers studies of the urban environment, farms, woodlands, seashore mountains. Projects include conducting a traffic survey, making a tree chart, collecting sea shells, as well as more active and demanding tasks from bird watching and photography to studying a pond or learning to fish. Mike Cotton's enthusiasm for his subject makes the book alive from beginning to end.

It is intended for use by handicapped young people, their parents and teachers, but any young person would find it of great interest.

Published by Human Horizons Series, Souvenir Press. Price: paperback £4.50. Casebound £6.95.

Incidentally a new series of booklet and packs designed especially to introduce environmental studies to mentally handicapped and slow-learning children are being produced by the Churchtown Farm Field Studies Centre. Entitled 'The Churchtown Book of . . .' they cover a range of topics from flowers and trees to pond life and city life and the first is on farms. Educational packs 'Churchtown Nature Project Packs' are also available. For more details write direct to the centre: Churchtown Farm Field Studies Centre, Lanlivery, Bodmin, Cornwall.

New Ways of Living

THIS booklet tells of the experiences of people with cerebral palsy, who have found satisfying alternatives to paid employment. It may be of interest to LINK readers following the feature on voluntary work in the March/April issue. The 14 contributors have used their diverse talents to take on voluntary work, fostering, weaving, lecturing, photography, gardening, fund raising, teaching and writing.

Published by the Spastics Society. Price £1 plus 25p postage, from The Spastics Society, Family Services and Assessment Centre, 16 Fitzroy Square, London W1P 5HQ.

Play for the Handicapped Child

A PAMPHLET for parents of all handicapped children—particularly those with mental handicaps—which aims to explain the value of play for such children. It suggests ways in which they can be helped to play, and in which play can help them. It contains a useful chart showing the kinds of play a child needs at different ages.

Available from Wiltshire County Council Education Dept., County Hall, Trowbridge, Wiltshire, BA14 8JB. Price 50p plus 15p postage and packing.

Help for the Handicapped Child

THIS is an attractive, easy-to-read and comprehensive guide to the voluntary and statutory help available for handicapped children in the London borough of Camden.

Other areas might like to look and take note of this publication produced by the social services department. Camden Town Hall, Euston Road, London NW1.

The problem of long journeys to hospital for treatment, the difficulty of integrating the children into normal schools, and the ignorance of the general public about spina bifida—these are some of the problems commanding the attention of the Spina Bifida Association in Spain, or as it is called the **Asociación de Padres con Hijos Espina Bifida (APHEB)**.



ASOCIACIÓN DE PADRES CON HIJOS ESPINA BIFIDA

APHEB has written specially for LINK about its work in Spain:

IN THE MAJORITY of cases children with spina bifida are seen and medically treated in the social service hospitals of the bigger cities.

This creates a serious problem of large numbers and results in long hours of waiting for some patients in order to see the doctor, and if we have to take into consideration those children who come to the hospital regularly then the problem is very severe.

Children living in rural areas and at a distance from the cities spend much of their lives travelling to the cities for check-ups and medical appointments, operations and treatment. These circumstances create severe problems for families who in many cases do not have relatives or friends in the city.

The fact that all the medical treatment is centred in the big hospitals is good from the technical side. Doctors there have already acquired a high degree of specialization and a great knowledge of the subject. The problem is to co-ordinate between the various specialist to give the children prompt attention.

It would be very convenient if there could be spina bifida units in all local hospitals to serve all the children with spina bifida in rural areas.

APHEB has as its ultimate aim the promotion of contact between associations providing mutual help to families. When parents first learn that their baby has spina bifida it is a great shock and is accompanied by anguish and distress. It is important in these first difficult moments that they have the support of other parents who have had the same experience.

APHEB is an organisation of parents and teachers whose main principles are: the provision of information on all the medical aspects of spina bifida by conferences, seminars and publications; to provide support to help parents to accept their child and give stability and help to them.

From the beginning APHEB has worked for the right of the child with spina bifida to attend normal school. In our country this is difficult enough as there already exists the belief that these children because of their physical disabilities need to attend special schools.

If the child with spina bifida is not able to live and participate in normal community life it is logical that it is in school where they will begin to make their first contacts with other people.

The child begins to mature psychologically by going to school with other children once he has reached school age. It is necessary that the child has contact with other children in order to acquire the social habits which develop and enrich his personality.

The schools role is not to be the sole provider of social life but the place where he begins his apprenticeship.

APHEB is conscious of all the difficulties of integrating the schoolchild with many and various handicaps but part of the resistance is due to the reluctance of teachers to have a handicapped child in a class where there are 35 to 40 pupils, and another reason is that many of these children have a lack of psychological motivation.

APHEB has devised a project for the child with spina bifida to follow in the school in order to help the teachers, who, if they put it into practice, will receive a subsidy from the administration.

Other activities of the Association are: the setting up of a sports club to encourage and promote the playing of sport between children and adolescents; and the setting up of a summer colony for children.

Also we intend to use all measures possible to spread information about the disability (by pamphlets, radio, press and TV exposure etc.) but this is difficult due to the ignorance which exists among the population about the malformation.

APHEB is encouraging and pressing for the creation of other Associations throughout Spain. There are already Associations in Zaragoza, Valencia, Madrid, Murcia, San Sebastian, and plans are well in hand for the formation of an Association in Tenerife in the Canary Islands.

The majority of statistics show that the incidence of spina bifida has increased, but in reality the number of newborn who are affected is practically the same. These children are taken to the city from maternity clinics to paediatric centres where they come under the care and control of the paediatric teams both medical and surgical who look after the majority of the population.

In our country we think there is an incidence of 1½ to 2% of all live births. We have seen that there seems to be 1,500 babies born with spina bifida. In the maternity homes of the social services in Barcelona there is an incidence of 1.25% of which generally it may be said that there is one spina bifida baby in every 800-900 births. This figure would suggest that the general practitioner might see two or three cases in 20 years who have a mild disability, but the actual hospital paediatrician might have 20 to 40 new cases annually and the special treatment centres for this disability would see 100 to 150 new spina bifida babies each year.



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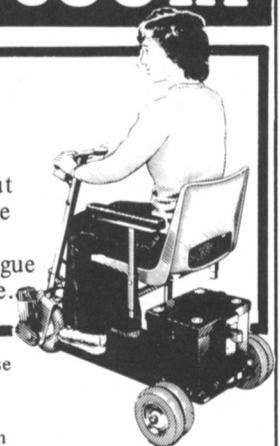
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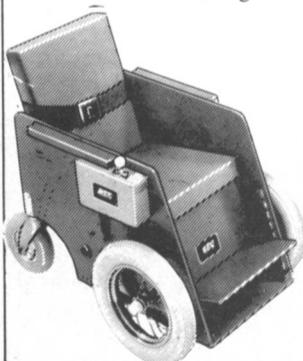


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In this the 75th Anniversary of the Scout movement, Alan White looks at the growth of scouting for those with disabilities.

Supertroopers

The scouting challenge
is for all

WOULD YOU believe that the Scout Movement is the largest youth movement in the world. Not only that but it was the second organised youth movement to be formed for boys (1907), the Boys Brigade being the first.

In 1926 the Disabled Scouts Branch was formed, later to be the Handicapped Scout Branch. This flourished, providing opportunities within Scouting for boys and young men mainly in special wolfcub packs and scout troops in hospitals and schools.

In 1967 the name was changed to EXTENSION ACTIVITIES and the scope extended to include the boy with a handicap in ordinary Scouting. This was no revolutionary change but a speeding up of the evolution which had been going on, enabling a more enlightened approach in Scouting *with* boys who are handicapped.

Many more boys with a handicap have found their way into Scouting with a marked increase among 16-20 year-old young men and women joining venture scout units. With able bodied youths they share the same programme, activities and opportunities on equal terms.

However there is still a large number of boys who still receive their education in special residential schools and there is still a need for the special scout groups. Where this does exist the boys are encouraged to join in the activities of the District where they participate with the able bodied.

The scout programme is designed to be flexible and can be adapted to meet the needs and capabilities of all boys.

Alternatives to the programme can be met by the unit leader in consultation with the district commissioner, the only condition being that the alternative is equally as challenging to the boys and that "whatever he attempts he does his best". This gives great scope even for those who unfortunately, are, confined to a wheelchair.

Generally speaking nothing special is laid on for the handicapped, the emphasis being on creating opportunities to do things together, going on hikes together, canoeing, sailing, gliding, climbing, camping, and joining in creative activities together. There are however a few exceptions to this; an Outward Bound course, a water activities course at the Scout Association's Water Activities Centre, near Marlow and a limited number of activities arranged in countries are run solely for the disabled.

'They can do it'

These are designed for those so severely handicapped that special facilities and increased staffing are required, and to stretch the boys to their limits, to prove to them "they can do it" and to prove to the public at large that the handicapped can participate in adventurous activities—often better than the able bodied.

All handicaps are accepted: the only condition of membership that applies is that he must make the Scout Promise or have an understanding of the Cub Scout or Scout Law, no matter how basic that understanding may be. If he cannot understand the Promise or



Law and communicate with his leader then this is the only exception to membership.

During the International Year of the Disabled there were no special events, fundraising or recruiting drives—it is our belief that we have **always** done our best for the handicapped and will continue to do so. What we did however was to increase our training provision for leaders working with the handicapped to encourage counties to appoint a Commissioner for Extension Activities where there was not one already and to make the public aware of our acceptance of the handicapped on equal terms.

Yet more importantly, this year, I have appointed a new 'Team' to assist me in examining our present policy, our methods, our support to the leader and to the scout, our publications and our training of leaders who work with the handicapped. We shall be continuing consulting other leaders, organisations concerned with specific handicapping conditions, the medical profession and the handicapped themselves. We shall have a special conference in February 1983 to which all our advisers and many others will be invited to share our ideas and ask for their help.



This year, 1982 is the 75th Anniversary of Scouting and it has been designated throughout the world as The Year of the Scout. We are to celebrate this in a rather special way with EXTOREE 82—an International and fully integrated camp at Gilwell Park on the edge of Epping Forest close to London.

It was originally planned that this would be a camp for about 1,000 all boys attending being handicapped, but it has now developed into an integrated camp where we expect an attendance of 2,000. Camping will be in patrols of five disabled, three able bodied, and two adults.

Full programme

The participants, male and female, will be between the ages of 11 and 20 and many will be from overseas. A full programme is arranged with sailing, canoeing, horse riding, and many "in-camp" activities and interest trips out of camp by coach. All of this is being made possible by a very devoted group of commissioners and scouters who have organised support teams to provide a good programme, first class catering and a medical team of qualified doctors and nurses.

We are also indebted to the many scout groups and organisations who have donated cash to make this a special event with the idea of giving the handicapped an opportunity to participate on equal terms and thereby to offer encouragement to other countries and organisations to follow our pattern.

If anyone, after reading this, possibly learning about our policy to extend Scouting to all boys for the first time, would like to know more or be put in touch with Scouting locally, they can write to me.

Alan White
Headquarters
Commissionaire for Extension
Activities
c/o The Training Department
The Scout Association
Gilwell Park, Chingford
London E4 7QW



HAPPY Paul Davis holds up the Bronze Medal he received in this year's Annual Achievement Award organised by the Spastics Society.

Paul who has spina bifida and hydrocephalus was proud to be picked from many scores of severely handicapped children from all corners of the British Isles. Ten youngsters reached the final and he was beaten to first place by 14-year-old Lindsay Gladwin from Norwich but was very happy with the Bronze medal. He received it in recognition of his fight against spina bifida.

Paul, 14, of Tilehurst, Reading, goes to Avenue School, Reading. He is in a wheelchair but certainly gets around. He is a very keen sportsman and has won many different sporting medals and trophies. Paul is also a member of the local PHAB club. He also finds time for hobbies—astronomy, tape recording and plane spotting.

Many congratulations Paul.

Stars entertain for Michelle

COMEDIAN Jim Davidson enlisted the help of a host of top entertainers and the result was a spectacular four-hour show at the Winter Gardens, Margate in May.

It was all done by Jim Davidson to raise money for 10-year-old Michelle Waters who has spina bifida.

The result was a £6,000 cheque which Jim handed to Mr Waters after the show to pay for a conversion on the family's council home in Faversham so that Michelle could have her own room downstairs.

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Community effort by the disabled produces new newspaper

A FOUR page newspaper produced by disabled people for disabled people and their friends has 'hit the streets' in Nottinghamshire.

Here Editor, Richard Musgrave writes about how the newspaper—which he prefers to call a newsletter—'Disaprint', was set up and the hopes for the future:

FOLLOWING discussion begun during IYDP, opinion in Nottinghamshire was that special effort should be made to ensure the disabled community in the region be kept fully aware of progress affecting their daily lives. IYDP was providing rich new sources of interest amongst not just the disabled, but non-disabled too. Continuing effort must be maintained, it was felt, in order that interest be carried forward through the difficult years ahead.

In conjunction with the IYDP Committee for Notts., the Nottingham Council for Voluntary Service brought together a small group of disabled people who, as individuals, had expressed interest in producing some kind of paper expressly for and by disabled people themselves. With considerable help and effort from the IYDP Committee's secretary

(Mrs Mary Perry) a meeting was held to appoint an Editorial Group. At the same time further work was being done within the county progressing the idea of a Disability Forum. Representatives from local groups concerned with disability meet together every 2/3 months and this will, it is hoped, encourage contribution towards DISAPRINT.

Finance for the paper was arranged through Nottingham CVS who applied to the special IYDP Fund set up by Notts. County Council. A Grant of £1,100 was made for four issues during 1982. Several other small donations have since been given: the largest being £150 from RADAR. In order to try and accommodate *all* types of handicap, DISAPRINT is produced using heavy quality paper and large style print. This has meant that print costs are considerably higher than first was anticipated. This year's issues may accordingly have to be reduced from four to three, unless additional financial support is found before the Autumn.

Local groups concerned with handicap or disability were

contacted towards the end of IYDP and asked if they would be interested in contributing to, as well as receiving, a quarterly Newsletter. Consideration was given to fully utilising existing suitable outlets for the paper and key departments within the fields of Health and Social Services were asked to help with distribution. In this way it is hoped that DISAPRINT will reach its potential readers through being widely available in Day Centres, Health Clinics, Libraries, Special Schools etc. in addition, the Family Practitioners Committee have very kindly agreed to circulate copies to all local GP's.

The paper is distributed free in Nottinghamshire.

Subscribers in any part of the country are invited to contribute a minimum of £1 towards receiving four issues per year.

DISAPRINT welcomes contributions towards its pages from any disabled person: either *short* articles, photographs, poems, cartoons, etc.—although strict preference will always be given to those contributors in the county of Nottingham.

HANDY CAPTION

devised by David Swift
drawn by Julian Wright

The life and difficulties of a disabled man



Disaprint has introduced a friendly strip cartoon character, Handy Caption who finds himself in all kinds of interesting situations. Reproduced from the pages of Disaprint Summer 1982.

A NEW non-profit making trust has been set up to organise and run tours and special interest holidays for mixed physical ability groups of adults.

Called the Project Phoenix, it has details of a variety of different tours for this year and 1983, and would like to hear as soon as possible, from anyone who is likely to be interested.

The tours vary from seven days to three weeks, and usually two half days a week are left free for individuals to do as they wish.

The tours scheduled so far, go to Tunisia, Florence, Southern Ireland, Rome, Greece and Leningrad.

Project Phoenix aims to organise groups of between 12 and 20, with a ratio of 1½ able-bodied helpers to 1 handicapped participant.

The cost will be kept to around £350 per person at a maximum, at the same time there will be a good standard of accommodation and facilities.

According to the resources of the Trust Fund, it is hoped to be able to offer, from time to time, some sponsorship for participants.

Phoenix designs tours to capture imagination

This could be an overall reduction in costs for everyone, or sometimes a grant to individuals.

The Project Phoenix study tours and holidays are essentially group activities. The group is entirely interdependent, and there is only very limited scope for individuals to go off and do their own thing.

At the same time, they are by no means totally regimented, nor are they like Colditz!

The Trust points out that the

visits are not 'do as you please holidays' but are structured to cater for those who enjoy learning something new, or extending their knowledge in a particular field, in company with other like-minded people.

More details from (stamped addressed envelope please): The Secretary, Project Phoenix Trust, 68, Rochfords, Coffee Hall, Milton Keynes MK6 5DJ.

Having a quiet rest at its moorings before setting off on another trip—John Grooms' narrow boat, which is specially designed to cater for physically disabled people. (See below)



More holiday news

THE GROWTH in holiday provision by John Grooms has been very rapid in the last few years. Now they are able to offer over 100 holidays a week to disabled people, their escorts, friends and relatives.

An unusual holiday is made possible by hiring John Grooms purpose built 10 berth narrow boat, moored on the Grand Union Canal near Hemel Hempstead.

Thanks to the London Borough of Barnet, John Grooms also have a motor caravan available to families with a wheelchair member to travel where they want without difficulty. It is kept at John Grooms in Edgware, Middlesex.

See advertisement on facing page.

KINGFISHER, the Spinal Injuries Association narrowboat, has proved so popular for family holidays that a second Kingfisher was launched this year.

Kingfisher I is based at Rugby, and the newcomer, Kingfisher II, is moored on the beautiful

Monmouth and Brecon canal.

Both boats have lifts fore and aft, ramps from ship to shore and even electronic steering which enables people with reduced arm strength to don the Captain's hat and take charge of the boat. They are completely accessible from stem to stern, and sleep five comfortably.

For more details contact the Spinal Injuries Association, 5 Crowndale Road, London NW1 1TU. Tel: 01-388 6840.

A NEW Hotel Guide for the Handicapped has been produced by Horizon this year. It is a simple, but very comprehensive guide to hotels abroad used by Horizon, showing their suitability for clients who are handicapped and in wheelchairs.

It lists the hotels, and gives a description of the situation 'hilly-slope to main road' and then information on suitable beach access, number of steps to the

public rooms, door widths, and inaccessible facilities. There is also a general comment on the suitability of the hotel—'easy access inside hotel as well as to town and beach'.

There are Horizon travel centres in Birmingham, Coventry, Croydon, Leeds, Leicester, Liverpool, Manchester, Nottingham where you could get a copy or at the London centre: 41 Old Bond Street, London W1X 3AF. Tel: 01-493 7446.

DON'T forget ASBAH has accumulated a good deal of information on all kinds of holidays. If you would like any help or advice at all about such things as individual or group holidays, special interest holidays, travel or insurance arrangements please contact Beverley Holland, Information Officer at ASBAH National Office.

DURING 1980 a number of disabled people began discussing the need for different national organisations of disabled people to come together in order to enhance our collective struggle for emancipation.

The previous decade had already seen a tremendous growth in organisations controlled by disabled people. A great deal had been learnt in those years and we felt much clearer and confident about the direction of our future work.

By now it was apparent to us that the initiative for developments in the future had passed out of the hands of professionals and traditional organisations and into the hands of the new organisations controlled by disabled people.

Early in 1981 a meeting was held which was attended by representatives from about ten of the major organisations of disabled people and we agreed to set up a steering committee in order to create a national coordinating body. Support was also offered by other organisations and the steering committee was reassured that the goal of unity was sought by the majority of disabled people.

It was agreed that it would be appropriate to inaugurate, what came to be called the British Council of Organisations of Disabled People (BCODP), during IYDP.

1980 had also seen the creation of an international steering committee of disabled people in order to set up an international organisation. This had been the outcome of the rejection by Rehabilitation International (RI) of an appeal by disabled people to have at least 50% representation on RI (so much for the RI concern about its own "Charter for the 80s" which advocates the integration of disabled people!)

The inauguration of the Disabled Peoples International (DPI) was planned for November/December 1981 and we were determined that the BCODP would be in existence by then so that we could join the international body and send our own delegates.

The BCODP inaugural conference was arranged on 7th November 1981 and disabled people from all over the UK were able to attend. This exciting gathering was attended by disabled people from some 15 organisations. A few weeks later three BCODP representatives went to the inaugural conference of DPI.

The BCODP was recognised as the official UK representative body and I was elected onto the World Council. Over 500 delegates from 51 countries attended and we came away with a tremendous feeling of confidence.

The DPI flexed its muscles and rejected the official WHO definition of impairment, disability and handicap and replaced these medical interpretations of our situation with ones which make it clear that the functional restrictions we face are imposed by society and not our bodies. The problem is *not* adjusting to our disabilities, as traditional professional practice would have it, but adjusting society according to our needs.

The BCODP accepts these concepts as central tenets in its philosophy. It is a coordinating body made up of independent national organisations of

British Council adds up to a Declaration of Independence

disabled people. Its function is to act as a forum for the exchange of views between its constituent organisations and to set in motion practical plans of action which will tackle specific social barriers to our integration into the community.

At the first council meeting it was agreed that action plans would be prepared in order to tackle (a) our housing needs, (b) our educational needs, (c) the need for a regular publication of the council, (d) the need for Centres of Independent Living, and (e) the creation of a central headquarters, which can accommodate all the organisations involved with the BCODP.

An integrated strategic national plan of action is also being drafted.

In my view the emergence of the BCODP was the single most exciting event of IYDP. In order to build on the momentum we have now created we are asking all disabled people to join organisations controlled by disabled people and to encourage these organisations to join the BCODP.

**by Vic Finkelstein
BCODP Chairperson**

ASBAH's young people's organisation LIFT has appointed more members to its committee. The membership is now over 50% disabled people. LIFT is considering applying to join BCODP.

JOHN GROOMS HOLIDAYS

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

Seaside Hotels: at Llandudno and Minehead • licensed • level access • emergency call system • balconies overlooking the sea • tail lift bus for tours • colour T.V. lounge • **(Bargain Winter Breaks for only £8 per day including VAT).**

Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton and Tenby. Equipped with ramps and other aids.

Holiday Chalet: Near Skegness (Lincs). Emergency generator for iron lung users.

London Holiday Flat: London, N4.

Motor Caravan: First season 1981. Can be hired for one or two weeks, and driven anywhere in Gt. Britain. It has tail lift, special wheelchair W.C./Shower unit, and other modifications. Black & White T.V. and Radio.

A Bungalow in the heart of the Norfolk Broads: 200 Yards from the River Bure, shops and station.

A Canal Holiday in adapted Narrow Boat:

For further details contact: John Grooms Holiday Department (Ref. L2.), John Grooms Association for the Disabled, 10 Gloucester Drive, London N4 2LP. Tel: 01-802 7272.

Glittering ball raises record sum

The main item of appeals news in this edition of link must, of course, be the Crown Jewel Ball which this year moved from the Dorchester Hotel to the Intercontinental and proved to be a most successful and happy occasion when we were once again honoured by the presence of our Royal Patron, HRH The Duchess of Gloucester.

Nearly three hundred people attended the Ball which featured an excellent dinner, a fashion show of clothes by Chanel modelled by twelve of London's leading beauties and compered by actor, singer/songwriter Mr Jeremy Nicholas. Dancing to The Dark Blues once again proved a great attraction and the financial result, including advertising revenue from the souvenir programme, should amount to a sum in excess of £13,000—an all time record for this event.



ASBAH's Patron, HRH The Duchess of Gloucester photographed at the Crown Jewel Ball talking with the Lady Jean Mackenzie, and Jeremy Nicholas, actor, singer/songwriter who compered the Chanel fashion show during the evening.

Keeping up the chat

The first day of May saw the promotion of the first ever Chatathon, held at The Law Society, London in aid of ASBAH. This was a marathon talk-in, designed to find the conversationalist of the year and many pairs of participants gathered to talk their way through an arduous 12 hours on Saturday, with four couples qualifying for the quarter finals on Sunday, 2 May. The final was judged by Mr Giles Brandreth who selected Mr Derek Coltman as the most deserving winner. Derek is employed by the Institute of Directors in the capacity of Director of Education and he and Mr Brandreth then repaired to the studios of LBC to broadcast an exhibition bout assisted by the runner-up Mr Howard Abramowitz. LBC covered the event throughout the two days and expressed themselves well satisfied with the standard of participation and organisation. The organiser, Assistant Appeals Director Ian Morrison, is already formulating exciting plans for extending the contest throughout the UK next year.

Police angle to the top

Maggie Corbett brought her nationwide angling contest to a most successful conclusion with a presentation ceremony at Fishmongers Hall at the end of April. The event in which many angling clubs throughout the country participated raised over £9,000 for the Association and the first prize was won by the angling team from the City of London Police. They generously donated the prize—a fishing holiday for two in Ireland—to Mark Jackson, who has spina bifida, is a keen angler and he will no doubt take full advantage of the award.

Ringling the changes

As the selling of advertising space has emerged to be a most lucrative source of income for the Association it was decided by Council and Executive to establish an in-house telephone sales department in order to eliminate the necessity for employing outside agencies and therefore this new department started trading on Monday, 7 June. The Manager of the new department is Mrs Sue

Owen and the sales team will initially consist of four representatives plus a further two clerical assistants and it is hoped that the success of this venture will be such that the department will expand in due course. If any local associations feel that they would like to avail themselves of this new service we would be most happy to co-operate in this way, but would appreciate early notice as it will be necessary to schedule the workload very carefully.



ASBAH's appeals activity seems to be growing at a most encouraging rate with new fundraisers bringing new expertise and original thinking to the ever increasing problem of acquiring adequate funding for the fast growing needs of the Association. Let us hope that this trend continues and all our efforts prosper!

JUDY KAY
Director of Appeals

CLASSIFIED 'ADS'

The advertising rate is:

£2.00 for up to 30 words. £3.00 for 30-45 words.

£4.00 for 45-60 words.

Please send remittance with your advert.

Adverts for the next LINK (Sept/Oct) should be in by August 10. 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).

HEYSHAM, Nr Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Shropshire. Tel: Whitchurch 3691.

MABLETHORPE. 2 fully equipped cedar chalets on Links estate. Sleep 6. Further details: Mr B Guest, 57 Bloxwich Lane, Walsall. Tel: Walsall 31725.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet. Indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

WITHERNSEA: Well-equipped 6-berth chalet at Golden Sands Chalet Park. Shop, licensed club, play areas, amusements on site. Details (sae please): Mrs P. O'Callaghan, 14 Dyer Lane, Wheatley, Halifax. Tel: 0422 56402.

ECCLES BEACH: Norfolk. Well equipped caravan, sleeps 6 and baby. Ramp for wheelchairs. Details: Mr Horsnell (see below).

EXMOUTH: Devon. Beautifully equipped 2-bedroom bungalow. Sleeps 7 and baby. Details: Mr Horsnell (see below).

GOWER PENINSULAR: Beautifully equipped 3 bedroom bungalow. Sleeps 8 and baby. Details: Mr G. Horsnell, 15 Reynards Way, Bricket Wood, St. Albans, Herts. AL2 3SG. Please send 4" x 9" S.A.E.

Herts and South Beds. Association.

MABLETHORPE: Purpose built 6 berth chalet. All mod cons. Easy access for wheelchairs to all entertainment. Details: Mrs J. Davis (see below).

PRESTATYN: Caravan, 6-berth, adapted for wheelchairs. Close to entertainments and beach. Details: Mrs J. Davis, 42 Mount Terrace, Eccleshill, Bradford.

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

Local Association changes

The following changes of Local Association Secretaries have taken place since the last LINK. A full Directory will appear in the next issue.

BRISTOL
Mrs Mabbut
20 Bramble Drive
Stoke Bishop
Bristol

LONDON N.EAST
Acting Secretary:
Mr C Pierson
18 Kingsley Road
London E7

MANCHESTER
CENTRAL
Mrs M Eccleston
77 Langport Avenue
Longsite, Manchester

SUNDERLAND
Mrs A Shepherd
115 Holborn Road
Sunderland
Tel: Sunderland 283568

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green family symbol and words 'Support Spina Bifida'. Sizes 22"-30": £2 each. Adult sizes, small, medium, large: £2.75 each. **Sweat Shirts** in reverse colours. Adult sizes, small medium, large, XL: £6.50 each, postage included. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Holiday Chalet Bungalow: 6-berth, fully furnished, situated adjacent to the beach at Millendreath, nr. Looe, Cornwall. Bungalow accessible to wheelchairs. £11,000. Full details from: Becketts, Bridgewater. Tel: 0278-423353.

ASBAH booklets etc . . .

Your Child with Spina Bifida,
by J. Lorber, MD, FRCP 35p
Your Child with Hydrocephalus,
by J. Lorber, MD, FRCP 35p
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
Paul 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, Hindi, Punjabi and Urdu.

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (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

Posters

Best Foot Forward 20 x 30 in. 10p each
Best Foot Forward 15 x 10 in. 10 for 40p
For local publicity 15 x 10 in. 10 for 40p
Car Stickers 13p each
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 items, i.e. pens, key rings, kits, games, etc. Send for list and order form.

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

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

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DELUXE POWERED WHEELCHAIRS

**Rugged dependability
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For young and old, this easy-to-drive electric wheelchair gives independence and freedom to those in need. Compact for indoor use, rugged for outdoor travel — up to 18 miles on a full charge. Copes with hills and kerbs. **AT NO EXTRA COST**, power-assisted seating adjustments and many other built-in "extras". Available through the **MOTABILITY** scheme for those receiving Mobility Allowance.



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