



Link

Association for Spina Bifida and Hydrocephalus/ASBAH

Jan/Feb 82

ASBAH wins special IYDP Award;

Southampton plans flats;
Prospects for true prevention;
Learning to drive the right way;
British Council of
Disabled People;
Pétanque; Appeals;
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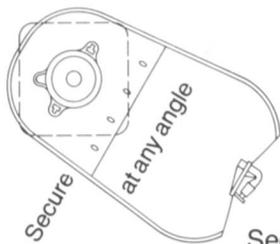


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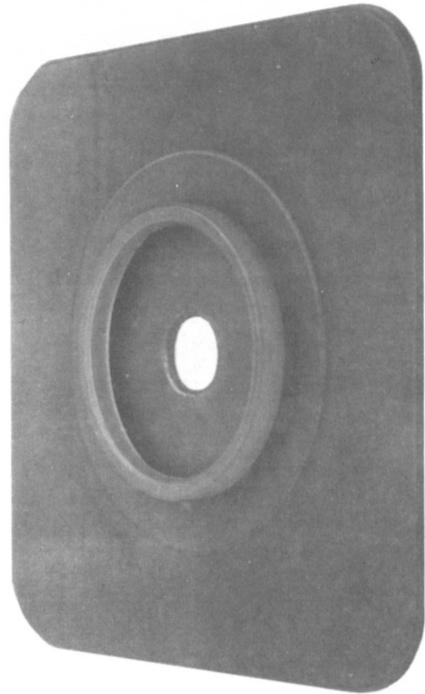
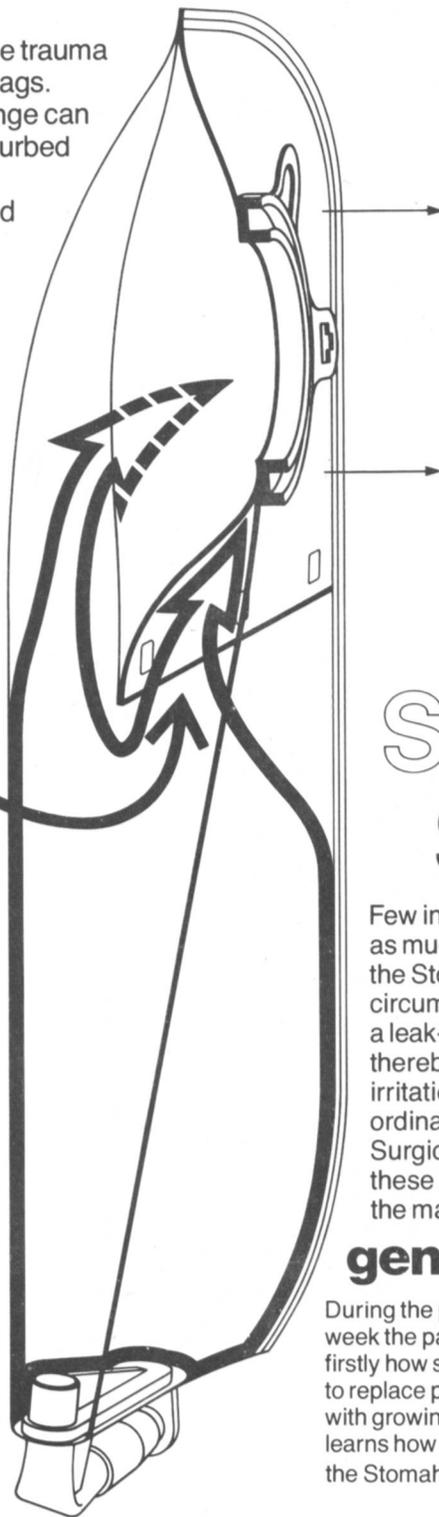
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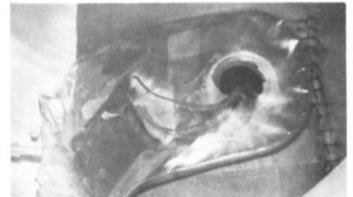
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ASBAH wins IYDP award

THE END of IYDP bought a very special honour to ASBAH—first prize in the Government award scheme for voluntary projects which have enhanced the quality of life for disabled people.

The award launched by the DHSS for IYDP went to ASBAH for its Social Rehabilitation Courses (independence training as it is sometimes called in LINK), which have led to the independence of a great many young people and their integration and participation in society.

A certificate and £1,000 were presented to Miss Moyna Gilbertson, ASBAH's Chief Executive Officer by Mr Hugh Rossi, Minister for Disabled People at a special ceremony at London's Lancaster House in January. The judges were chaired by Sir Kit Aston, and included Brian Rix of MENCAP and Elizabeth Fanshaw of the Disabled Living Foundation.

ASBAH's social rehabilitation courses have been extended and modified since they were started and now help younger children, too. At least seven courses are planned this year at Five Oaks and other centres.

ASBAH staff are also going into schools to help train staff and develop the curricula. Some helpers on ASBAH courses have gone on to become the organisers of further courses in different parts of the country.

Ann gets her clarinet

THE PROFESSOR Zachary Fund played Father Christmas to 10-year-old Ann Cleary, and bought her a very special present—a clarinet of her own.

Ann who lives at Earl Shilton, Leicestershire wrote and asked ASBAH if they could help because her interest in the clarinet was costing her parents a lot of money.

"I would like to ask if you could help them to pay for a clarinet or some lessons.

"I have been playing the clarinet for the last three months and enjoying it very much. My teacher is very pleased with me. Now I have been asked by my Sunday School teacher if I could play for the class as we don't have a piano-player every week. They have also asked if I would like to play in my Steadfaster Group..."

ASBAH did help. When Professor Zachary retired as Chairman in 1977 he asked for a special fund to be set up to help young people with spina bifida and hydrocephalus. It exists to help pay for such things as musical instruments, equipment for hobbies or sport, to help with travel, or books.

Professor Zachary particularly asked that the money be used to sponsor projects initiated by young people, and the trustees prefer to hear from the young people themselves.



Ann Cleary—pictured with her brother—enjoying her special Christmas present from the Professor Zachary Fund—a new clarinet.

WE APOLOGIZE for the late publication of this issue of LINK. We had hoped to bring out a special supplement with this Link, but this has not proved possible and it will appear with a later issue.

FRONT COVER:

Fifteen year old Julie Weldrick gets a tow on roller skates from her younger sister, Joanne, 13, in her new, speedy electric wheelchair, bought by relations and friends. Julie found she couldn't keep up with her sister as she whizzed round in her chair in their home town of Barnsley. So mum and dad bought her a pair of roller skates, and Julie hitches a ride.

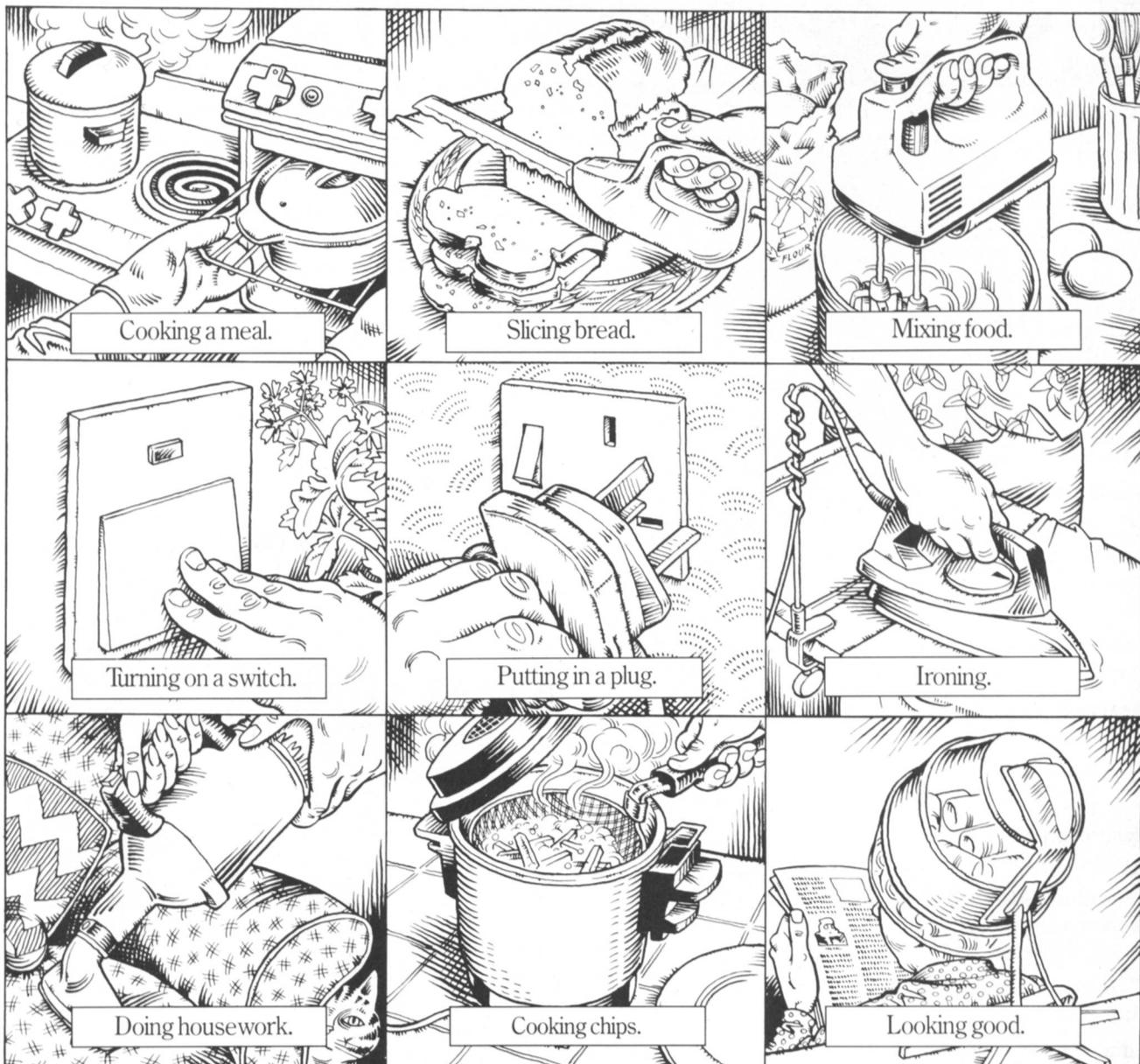
Photo: Barnsley Chronicle

HANDS UP everybody who spotted the difference on our front cover. It's the *Bell* in the top right hand corner of the page. Through 1981 LINK carried the symbol of IYDP. Now, in 1982, we are planning to use ASBAH's own symbol—and it's a new one. Following the successful use of the *Bell* in appeals campaigns ASBAH has decided to use it on a permanent basis.

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Is it this easy in your home?

At your Electricity Board, we have a leaflet called "Making Life Easier for Disabled People".

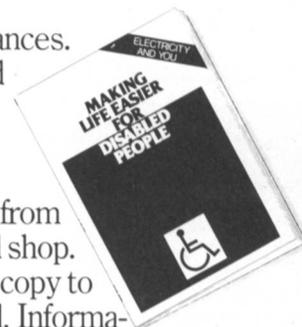
It contains lots of helpful ideas and lists many electrical appliances which can make life easier.

Appliances such as table-top mini cookers. Electric knives which require only a slight pressure to operate. And small, hand-held vacuum cleaners which can be used for dusting, too.

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.



THINKELECTRIC

The Electricity Council, England and Wales.

Good news on home front

GRANTS to cover between 75% and 90% of the cost of house adaptations for disabled people have been introduced from the beginning of the year. Mr John Stanley, Minister of Housing and Construction, speaking at Naidex in the Autumn said that he would be seeking approval to make the 'priority rate' of Improvement Grants available for house adaptations for disabled people.

Formerly this rate was only available for improvements to seriously sub-standard housing.

The grant can cover 75% of the cost or 90% in cases of financial hardship.

IYDP—call for action now

A DECLARATION on the Prevention of Disablement was published in November at the end of a four-day international seminar held at Leeds Castle in Kent. It summarises the unanimous recommendations of scientists, doctors, health administrators and politicians attending the seminar on immediate action to follow up the International Year of Disabled People.

Copies can be obtained from the Department of Health and Social Security, Elephant and Castle, London SE1 6BY.

. . . and over next two years

CHARTER for the 80's—the statement for action during the next ten years to follow up IYDP—has been presented to heads of state and governments in all parts of the world.

In November it was presented to His Holiness Pope John Paul II by the President of Rehabilitation International, Dr Harry Fang. It was Dr Fang who made the presentation to Mrs Thatcher the following week at Downing Street. LINK reported on the Charter in the last issue. Free shortened versions are available from National Office.

Wanted—special 'play-aids'

PURPOSE designed 'play-aids' of special value for handicapped children are being sought for a special Play-aids Exhibition to be held in Newcastle upon Tyne in May and then to go on tour.

Designers, research establishments and the general public are asked to send in prototypes, plans, slides or simply ideas for items such as playclothes, educational aids, electronic devices, musical toys, mobility and communication aids, furniture, puzzles etc. The final date is March 26.

Prototypes should be of a manageable size and shape so that they can be easily delivered or posted.

The Exhibition is being organised by the Handicapped Persons Research Unit.

The address for more details, or for sending your ideas, is HPRU, Newcastle upon Tyne Polytechnic, No 1 Coach Lane, Coach Lane Campus, Newcastle upon Tyne, NE7 7TW. Tel: 0632 664061. The contacts there are Ed Wilson or Mick Lannen.

104 companies win awards

OVER 100 companies, ranging from large well-known organisations such as the National Coal Board and British Petroleum, to small manufacturing companies, received the 1981 Manpower Services Commission's 'Fit for Work' Awards, given in recognition of their achievements in employing disabled people.

A national Judging Committee, under the Chairmanship of Sir Geoffrey Gilbertson CBE, chose 104 employers from all parts of the country, as winners of these Awards.

Sir Geoffrey said he was extremely encouraged that a substantial cross-section of industry and commerce had been among the 412 applications received from employers.

Time to honour achievement

IF YOU KNOW of a handicapped child, between the ages of 5 and 16, whose determination and courage in the face of adversity fills you with admiration, please contact The Spastics Society.

The Society is seeking nominations for its Annual Achievement Award, which is open to children suffering from any type of handicap. The citation is for 'the bravest or most outstanding effort, or achievement, in any field by children either born handicapped, or who have suffered handicap by the age of 5'.

Degree of handicap is taken into consideration by the panel of judges so that all entrants compete on equal terms.

The winner of the Award will receive a prize of £250 and a silver cup. There are also second and third prizes of £50 and £25 respectively. All finalists will receive an inscribed medal and will be invited, with their escorts, to a celebration lunch in London and to the ensuing Award ceremony, with all expenses paid.

Closing date for nominations is 1st March 1982.

Nominations etc. to Mrs Nina Heycock, 35 Harrington Gardens, London SW7 4JT, who is organising the Award on behalf of The Spastics Society.

Technology and disability

A CONFERENCE concerned with tomorrow's technology and its application in the field of disability is being organised by the Spastics Society at the new Brighton Conference Centre in September.

Distech 82 is a follow-up to the first Distech conference last year. It will be concerned with mobility and transportation, communication, learning, play and aids to daily living.

It will appeal to all professionals concerned in providing accommodation, services or care for the disabled. Details from The Conference Secretary, *Distech 82*, The Spastics Society, 12 Park Crescent, London W1N 4EQ.



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Southampton decides to build flats

AN AMBITIOUS scheme to build a small block of specially adapted flats is keeping Southampton and District Association well and truly busy.

The association in Southampton felt it ought to provide accommodation for teenagers who would soon be wanting to lead independent lives, so an Independence '81 appeal was launched to raise about £100,000.

"A local charitable housing association at Swaythling gave us invaluable help. They advised us of a plot of land for sale. We bought it, and now have two rather pale-faced trustees" said the association Secretary, Mrs Connie Taylor.

The land is in a good position at Portswood on the outskirts of Southampton. The housing association will arrange for the building of the units—both singles and doubles—and the association will use the rent from the flats to pay off the mortgage. Central Government has agreed to give generous financial help.

The appeal itself—centred round one of the teenagers, Tina Billet—has got off to a great start and is being co-ordinated by

ASBAH Appeals Organiser, Madeleine Legg.

Connie Taylor told LINK: "The mainstay has been Radio Solent. If they had not agreed to help we could not have gone ahead with the appeal. A staggering half a million leaflets and envelopes were printed by Southern Gas. The aim was to put one through every door in the Radio Solent listening area.

Radio Solent was fantastic, and so was the response. The phones never stopped ringing and they were manned by volunteers from 6 am to 6 pm."

The culmination of the appeal was Jamboree Day in Hoglands Park, Southampton. People were asked to bring their envelopes, containing money, and hand them to various celebrities. It was also to be a 'fun day' with marching bands, jazz bands, majorettes and bunny girls, but unfortunately the weather was appalling and had the effect of dampening the response and the fun.

However, money is still coming into the office and the organisers are hopeful that by the end of the year, about £35,000 will have been raised.



Scotland has new head

NORTH of the border, the Scottish Spina Bifida Association is starting another busy year—and 'at the helm' is a new Executive Officer, Mrs Audrey Smith (above).

She has been able to bring to the job a wide range of experience, as a teacher, administrator and counsellor.

After a teaching career of 15 years she joined the Scottish Spina Bifida Association in March 1979 as one of its National Counselling Officers.

Mrs Smith told LINK "During the period I spent as a Counsellor, I was continually learning about the Association, the difficulties of a family with a handicapped member, and above all about spina bifida. I feel passionately about people of any age being able to lead a full and worthwhile life.

"I thoroughly enjoy my post as Executive Officer; it is most absorbing, very demanding and full of variety."

Mrs Smith is married with two teenage daughters. She took over in June on the retirement of Mrs G B McIntyre from her post as General Secretary.

Andrea's prize

CONGRATULATIONS to 14 year old Andrea Bird of Cannock and Walsall Association who was awarded a prize for physical education at her school—Manor Farm School, Walsall. She was the only one in her form to receive an award. Despite her handicaps and her inability to take part in strenuous exercise Andrea gets great enjoyment out of swimming.

ASBAH reaches out to Asians

ASBAH IS aware of the isolation of some Asian families in this country who have a member with spina bifida and hydrocephalus.

To help in contacting some of these families a simple fact sheet has been produced and translated into five Asian languages—Hindi, Urdu, Punjabi, Gujarati, Bengali.

It gives information about spina bifida and hydrocephalus, and the facilities offered by ASBAH, locally and nationally.

ASBAH is grateful to the Commission for Racial Equality who translated and printed the fact sheets.

They have been sent to Field Workers, and could be useful for doctors, clinics and other services in areas of Asian population. Copies are available free from National Office.



A HAPPY wedding day picture for Keith Marshall and Sharon Galner. The couple, both of whom have spina bifida, were married in the Autumn at Elmstead Lane Baptist Church, Chislehurst. Keith is from West Wickham, Kent, and Sharon, from Brighton.

Photo: Bromley Times.

JEAN Slater, was living with her parents and had never seriously considered getting a home of her own. Then, through the **Trafford Federation of Clubs for the Disabled**, she heard of a flat for rent, one of two specially adapted in a complex of ordinary flats. She decided to have a go . . .

The flat I discovered was very near to where I worked and I knew the builders were still there and decided to have a look round in my lunch hour.

I was very impressed, it was obvious the Housing Association had tried to think of everything. The outside approach was ramped and there was a place to park my car right outside the door.

Inside everything was at the right level which makes things easier to manage. The bath was low and there was a bar to help you get in, the only thing I found wrong was there was nothing to hold onto near the toilets, but this was soon put right when I mentioned it.

I went home and told my

parents. I said I would try and get a key so they could see it for themselves. When I rang I was amazed to be told there were not many people interested.

I wanted my parents to know that it was not a case of not being happy at home, but we all knew that sooner or later I was going to have to manage on my own. The opportunity seemed too good to miss.

The decision made, I then went shopping for my furniture and everything else. I must admit I really enjoyed this part but you don't realise how much there is to think about—things like making sure the pans are not too heavy, or making sure the wardrobe is not too high.

I also had to make sure I had room to get around in my wheelchair but still had somewhere for people to sit. I got round that one by getting a two seater settee,

an easy chair and also some fold-up chairs.

I moved in nearly a year ago, and up 'til now I have managed quite well. I find I can do most things from my wheelchair. Of course I cannot hang curtains, or change a light bulb, but there is always someone willing to help and I also have a 'phone in case of an emergency.

Before I moved I was a bit worried about being lonely. But I need not have been as I have had lots of visitors and it's really nice to have a home of my own and to be able to invite my friends any time I like.

Jean Slater is Secretary of Trafford and Salford local association. This article first appeared in the Trafford Federation of Clubs for the Disabled Newsletter.

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The prospects for true prevention of spina bifida and related abnormalities

K. M. Laurence, Professor of Paediatric Research, Welsh National School of Medicine, Consultant Clinical Geneticist, University Hospital of Wales, Cardiff.

IT HAS been suspected for some time that the poor or disordered diet of a mother in early pregnancy may be one of the more important causes of spina bifida. The fact that the group of abnormalities to which spina bifida belongs is more common in the deprived regions of the United Kingdom, such as Northern Ireland, South Wales, Merseyside and the South West of Scotland and within these communities tends to affect the children of semi-skilled and unskilled workers points in this direction.

It has also been known that in times of semi-starvation, as in Boston during the great depression and in Berlin immediately after the war, the numbers go up and as the standard of living of the general population improves, the incidence tends to fall. This has been happening in Britain during the last decade.

A detailed investigation of the diet of mothers who had given birth to a baby with spina bifida was carried out in South Wales over 10 years ago. It showed that many of these mothers were taking an unsatisfactory diet and that during the first part of the pregnancies which ended in abnormal babies, the diet was quite a lot poorer than in those ending in a normal baby.

Following this finding, intensive dietary counselling was given to a proportion of the women which resulted in a considerable improvement in the majority and in a reduction of the number of recurrences. Indeed, the only recurrences amongst the 186 pregnancies which were studied were amongst those women who remained on an unsatisfactory diet.

What is it in this unsatisfactory diet that causes mothers to have a recurrence? From animal experiments carried out many years ago, it had been suspected that folic acid deficiency might be one of the causes. Folic acid is one of the vitamin B group of substances found mostly in green vegetables and salads, wholewheat and meat and especially liver. Suspicions were increased by the findings in mothers who, over 20 years ago, were given a therapeutic abortion with a powerful anti-folic acid agent. There were a number of "failed" abortions, where the

pregnancy resulted in babies with serious neural tube defects instead.

This and other evidence prompted by our South Wales team to try the effect of giving folic acid to mothers before they actually started a planned pregnancy. Over 900 mothers, all of whom have previously had a child with a neural tube defect, were visited in their homes and if they were planning more family and were willing to join the trial they were allocated to take either tablet A or tablet B. Neither the mothers nor the investigators knew whether it was tablet A or B which contained the folic acid until after the trial was over.

They were asked to take the tablets from at least the first day of the monthly cycle during which they hoped to achieve the pregnancy. They were requested to report pregnancy immediately they were reasonably sure when they were visited by a member of the team and they had to continue taking these tablets until they were three months pregnant.

In the event, 44 women who took tablet A which contained the folic acid achieved a further pregnancy during the period of the trial, all without recurrence of spina bifida or other neural tube defect. The 67 women who were allocated to tablet B, the dummy or who did not take the tablets as instructed had 6 recurrences.

This statistically significant result suggested that folic acid given in sufficient amounts before pregnancy is actually started, acted as a protection against a recurrence and that folic acid deficiency was a cause of these abnormalities. It must be emphasised however, that the number of women in the trial was rather small and that folic acid deficiency, though probably an important and perhaps the most important cause in Britain, is almost certainly not the only one.

The South Wales investigation was carried out on rather a small number of pregnancies. Because of this, the Medical Research Council is considering financing and organising a large scale investigation of the effectiveness of a number of different tablets, including folic acid and multivite given before and during the first part of pregnancy. Over 20 centres in England, Wales and Scotland will be participating in the hope of confirming the South Wales findings as quickly as possible. It is expected to begin this trial early in the New Year when mothers who have had a baby with spina bifida or one of the other neural tube defects will be asked to participate and take tablets before they start a further pregnancy.

If the South Wales findings are confirmed, then a method of preventing recurrences of spina bifida in mothers who have already had an affected baby will be available. Folic acid is sufficiently cheap (less than £2 for a year's treatment) and safe to enable it to be offered for all planned pregnancies, regardless of whether there is an increased risk of spina bifida.

With improvement of the diet of our young mothers by health education, begun in schools and supplementation on a wide scale, we have the prospect of greatly reducing the number of spina bifida cases in our population. Hopefully, there will then not be any need for screening, early parental diagnosis and termination and, worst of all, the agonising decisions when an affected baby is born.



In August 1981 it was announced that young people receiving the Mobility Allowance are now able to apply for a provisional driving licence at the age of 16, rather than having to wait until they are 17. Obviously, this is very good news, as independent mobility is vital if young people are to make the most of local opportunities for leisure activities or training. However, for many, the current situation is very bewildering—"How do I get a licence?", "How do I know if I'll be able to drive?", "What kind of car adaptations will I need?", "How do I find a driving instructor with an adapted car?", "Which of the Motability schemes would be best for me?", "What happens if I give up my Mobility Allowance to get a car through Motability and then find that I can't pass my driving test?".

APPLYING FOR A PROVISIONAL DRIVING LICENCE

You are not allowed to attempt to drive a car on the road until you have a provisional licence. You should get an application form from a post office, fill it in and send it to the Driver and Vehicle Licensing Centre in Swansea. You are legally obliged to declare any disability that you may have.

The Medical Advisory branch may then contact you, asking for more details about your disability, and asking permission to get in touch with your GP or hospital consultant. If you have a "non-progressive limb disability" such as paralysed legs resulting from the effects of spina bifida then you will probably be granted a provisional licence restricted to "vehicles of all groups with all controls fitted so that they can be correctly and conveniently operated despite weakness of the lower limbs". If you have hydrocephalus and have a history of "fits" or epilepsy then the Medical Branch will have to consider carefully whether you are safe to drive, and will only issue a licence if you have been free from attacks whilst awake for at least the previous three years.

LEARNING TO DRIVE

Non-handicapped children start to learn "road sense" by being able to get out on bicycles in their home area. However, many disabled children who use wheelchairs never go out on their own and so miss out on general experience such as learning to recognise road signs, and to make decisions in traffic. We hope that new ideas, such as the Wheelchair Proficiency

Learning to Drive On the road

by JILL VERNON, D

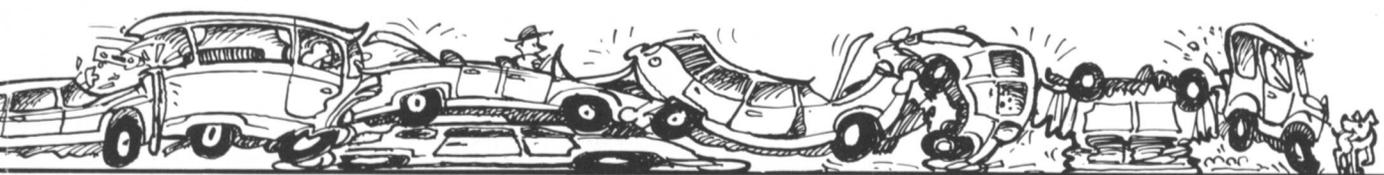
Scheme (announced in Nov/Dec LINK) will improve this situation in the future.

Also, some young people with hydrocephalus may have perceptual problems and difficulties with lack of concentration, and slow reaction times, and so the task of learning to drive later on may be much more difficult, and some may decide that they do not want to drive at all. You may not be sure about your ability to drive, and you may not want or be able to commit yourself to owning a car. We hope that the new Mobility Centre at Banstead Place will soon be able to provide an initial assessment and advice if you are in this position. The British School of Motoring has an assessment centre in London, but although they can give useful advice, for example, about sophisticated controls for people with very severe limb disabilities, they are not in a position to assess the more subtle effects of hydrocephalus. For many of our members an assessment at Banstead Place, or a trial lesson with a good instructor will be more appropriate.

If you are lucky enough to have your own adapted car then any qualified driving instructor should be able to give you lessons in your own car. Unfortunately, at the moment very few driving schools have automatic cars fitted with hand controls. The Disabled Drivers Motor Club have compiled a list and we at ASBAH are trying to add to it. If you would like a copy of the list, or can give us information about facilities in your area to pass on to others, please write to me at the National Office. Perhaps your ASBAH group could pay for hand controls to be fitted to a driving school car to benefit local members?

There are also driving simulators in various parts of the country, and Motability has paid for several of these to be fitted with Reselco hand controls. You have a series of five "lessons", watching films and responding to verbal instructions. This provides a useful and cheap opportunity to start to learn about





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driving before you go on to have lessons on the road in a real car. So far there are adapted simulators in Camden, Southwark and Leatherhead.

If you are thinking about getting your own car and you receive the Mobility Allowance, it is worth considering the various alternatives available through Motability. There are now schemes for leasing and buying new and second-hand cars, and also for buying outdoor electrically powered vehicles. As Motability is a charity, they may also be able to provide some help towards the costs of adaptations or driving lessons in cases of special need.

(MOTABILITY, The Adelphi, Boundary House, 91/93 Charterhouse Street, London EC1M 6BT. Tel: 01-253 1211).

TAKING YOUR DRIVING TEST

In order to pass your driving test you will have to prove your competence in the same way as anyone else. However, disabled drivers should be given priority when booking a test appointment, and extra time should be allowed to give you time to get into the car, and explain any special controls to the examiner.

FACILITIES AT BANSTEAD

In June 1981 Barbara Newman from ASBAH attended the formal opening of an exciting new venture, Banstead Place Mobility Centre. As you probably know, Banstead Place is part of the Queen Elizabeth Foundation for the Disabled, and provides residential assessment for physically handicapped school leavers. The facilities at Banstead have now been extended to include an outdoor "off the road" driving track, with a roundabout, T-junction, and traffic lights, and authentic road markings and signs. A Mini automatic with hand controls is available, and also a variety of outdoor battery powered wheelchairs. An electronic car simulator has also been installed to

measure hand or foot reaction times, braking pressures and steering forces.

So far these facilities are only available to students at Banstead Place. However, it is hoped that they will soon be able to offer a service to members of the general public. Disabled people and professionals would be able to ask for advice about mobility problems, and visit to try out the various types of powered wheelchairs and other vehicles. They also hope to provide a full day assessment for those thinking of driving for the first time, or wanting to drive again after an illness or accident. This could include a neurological assessment with a medical consultant, and testing by an orthoptist and a psychologist, as well as the more usual physical assessment and advice about car adaptations.

THE CANADIAN WAY

As part of my Churchill Fellowship travels last year I visited the Ontario Crippled Children's Centre in Toronto, where an excellent "Driver Training Programme" has been developed over the last five years. We still have a long way to go in this country . . . !

In Canada everyone has to learn about the theory of driving and gain a diploma before they can take their practical driving test. The OCCC course is spread over 10 weeks, with 25 hours of classroom theory, and 20 hours behind the wheel. Margaret Young, an occupational therapist, co-ordinates the programme, organising medical assessment and advice about car controls and seating before students are enrolled. The American Automobile Association has developed equipment for testing reaction times, and visual abilities, and this has been adapted for people with various handicaps. Two experienced driving instructors are available, and they can provide extra private lessons if necessary!

If students live a long way from a centre they can complete the classroom theory at their local high school, and then arrange to start at OCCC for 3 weeks in the summer for an intensive course of driving instruction.

Current projects at the centre include research with people who have suffered head injuries, and a follow-up study of drivers who have successfully completed the training programme. They are also producing a film of their activities, and we hope to be able to "import" a copy to show people in this country.

Continued on page 12



British Council of Disabled People comes into being

A voice of our own

REAL power for and decision-making by disabled people—that's the aim of a newly formed movement in Britain.

"It's no longer on for organisations of non-disabled people to be making decisions for us who are disabled" said Vic Finkelstein who is spearheading the establishment of the British Council of Disabled People (BCODP).

The steering committee of which he is Chairman is made up of representatives from national organisations of disabled people. The aim is to involve people with all kinds of disability, physical and mental, and to draw them into the

decision-making structures in this country.

"We hope that at last we will have in Britain a united voice of our own" said Mr Finkelstein. "Although much that was achieved during IYDP was the same old story of other people providing services for the disabled, the Year has given us a springboard for development and a chance to change things."

The council's first job is to find financial backing and an office, and then establish the priorities for action.

Internationally the movement towards action by disabled people

has started too. A World Congress of Disabled International was held recently in Singapore and attended by 400 disabled delegates from 51 countries. A World Council has been set up, and at present the representatives from Britain are Vic Finkelstein, Stephen Bradshaw from the Spinal Injuries Association and Francine White, Secretary of the Association of Blind and Partially Sighted Teachers and Students.

The British Council can be contacted, for the time being, at the Spinal Injuries Association, 5 Crowndale Road, London NW1 1TU. Tel: 01-388 0232

Some home truths

LETTER

HAVING read Gary Brayne's letter, both in LIFT and LINK (Nov/Dec), I simply must take issue with it for it strikes me as a glaring anomaly when he says that 'many people in the poorer parts of the world are disabled by diseases which can be prevented and also by poor diets'.

Now I, too, am concerned about the Third World and we should count our blessings, but the implication seems to be that our affluent western society is conducive to good health when, in fact, the exact opposite is beginning to be considered—that modern methods of producing food and modern life style may be killing us!

And if the findings on spina bifida of Professor R W Smithells have any substance it may even be that a sizable proportion of our own population is being crippled by the same malnutrition—albeit more complex—that handicaps Third World people. (How ironic then that this letter should appear in a spina bifida publication!)

So let us not be muddled in our thinking, for it

seems to me people are horrified to see on television Third World children horribly deformed by malnutrition and contribute huge sums of money to try to prevent this while under their noses in the British Isles are thousands of severely deformed children who will spend their entire lives in wheelchairs and incontinent.

In my opinion much of this could be prevented, which is where Helen Carthwaite's letter comes in (LINK Nov/Dec). I endorse her remarks about the Government opting out of its responsibilities regarding handicap.

I think people in general—and especially the Government—are far too complacent about pregnancy and childbirth. If better state care was taken of expectant mothers and no woman had to endure stressful situations during pregnancy because of lack of cash, and school-children—especially girls—were better educated in health matters, I am convinced congenital handicap would be dramatically reduced.

Teresa Anne Hehir
Belfast



Continued from previous page

ASBAH MOBILITY ADVISORY SERVICE

The situation is complicated and for this reason ASBAH is hoping to employ a part-time Mobility Adviser, probably working with the staff at Banstead Place. Meanwhile if you have any queries or would like more information about ideas in this article, please write to me at National Office.

The following publications also provide guidance: "Motoring and Mobility for Disabled People", by Ann Darnborough and Derek Kinrade, £1.75 inc. p & p from RADAR, 25 Mortimer Street, London W1N 8AB. "Disabled Drivers' Motor Club yearbook" £1 inc. p & p from DDMC, 9 Park Parade, Gunnersbury Ave, London W3 9BD. Tel: 01-993 6454.

JILL VERNON Disabled Living Adviser

BOWLED OVER— by Pétanque

Lesley Hancock from the Hexagon day centre in Southampton throws a little light on this popular game.

ANYONE who has spent a holiday in France will no doubt have noticed small groups of people playing a game which seems in some ways like bowls, but instead of smooth green turf it is played in car parks or dusty areas in parks, in fact on any spare patch of land. They are playing the second largest participant sport in France—Boules.

This game is now becoming extremely popular in Great Britain, but here it is called Pétanque.

Why should this be of interest to disabled people? Simply because it is one of the few sports in which disability is no disadvantage. It can be played by someone in a wheelchair—it can be played by someone with use in only one arm.

I have even seen it played and played well, by someone with no legs and only rudimentary hands at shoulder level. As long as there is some functional movement in one



Hexagon Centre's Pétanque club in action. Picture taken by members of the day centre's photographic group.

arm an attempt can be made. Great strength is not required.

Of equal importance is the social aspect of the game. Players come from all walks of life and all age groups. Groups have formed in clubs, offices, colleges and pubs. Many local authorities are allowing terrains to be provided in parks and many pubs have their own pitch—especially pubs owned by Whitbreads the brewery.

If any disabled group can find an area to put aside, it can enable them to invite other teams both disabled and able-bodied to come to a match and in return can be asked to play at various locations in their area, thus opening up the scope of social contacts.

For more details contact the British Pétanque Association: Sans Hotel, Shedfield, Southampton, Hants.

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SINCE the last Appeals report in LINK, life has continued to be as exciting and hectic as ever in the fundraising department at ASBAH.

Christmas always gives us every cause to be grateful to the very many loyal and generous supporters of ASBAH throughout Great Britain and indeed overseas, who respond so unfailingly to our appeal for help during the festive season. 1981 was no exception and, despite the hardship of the recession, contributions flooded into ASBAH and, unlike some other charities, our Christmas card and gift marketing has not suffered unduly.

Money has now been received, too, from The Dickinson Robinson Stationery Group. The photograph (below) shows Mr Ron Fisher, Product Group Manager, presenting me with a briefcase containing £5,000, which was their contribution to the Association in respect of the Celebrity Graphology Contest which appeared in the national press during the summer months.

The picture also show Mr Barry Cryer who kindly agreed to judge the tie-breaker, which was to suggest a suitable clue as to the identity of Miss Elaine Stritch. The winning entry was "chain letter is rewritten for me" which Barry had no hesitation in choosing as being an outstandingly clever anagram. As a result, the lucky winner set



Leading national clairvoyant, Medeline Montalban (left) and Jo Logan, Editor of Prediction magazine at the Crystal Ball.

sail on the P & O liner, the SS Canberra, to enjoy the prize of a two-week cruise, generously provided by Queens Velvet.

Barry Cryer was also with us once again, as our mystery celebrity guest, on the occasion of the first ever *Crystal Ball—A Night of Prediction*, which took place at the Café Royal on Hallowe'en—31 October 1981. The evening, attended by nearly 300 guests, proved to be a most exciting and enjoyable one with the added benefit of an opportunity to find out what the future holds. Fourteen experts in the various arts of clairvoyance were present and donated their services for private consultations on payment of a modest fee.

Those who availed themselves of the opportunity to have their futures predicted were astounded

Signs of good things ahead—we hope!

by the revelations. The clairvoyant that I spoke to predicted a successful year ahead and in this new year issue of LINK, I hope I have rightly interpreted this to mean that the affairs of ASBAH will continue to increase and multiply.

Now, back to Barry Cryer. His involvement with the Association continues and one marvels that he is not getting tired of us by now. He has now taken on the chairmanship of a very unusual fundraising event. Following the success of the photographic auction held at Sotheby's over a year ago, we have once again been fortunate enough to be allowed the opportunity to conduct an auction at their august premises.

This auction, which at the time of writing had yet to take place, is quite a departure for the country's best known sale rooms. Twenty stars of stage, screen and television have allowed themselves to be put up as "lots".

These stars have most generously agreed to donate their fees from one personal appearance and those attempting to purchase our celebrities will be captains of industry and commerce. Amongst those who have accepted the invitation to be sold in order to raise funds for ASBAH and The Muscular Dystrophy Group of Great Britain, are Petula Clark, Donald Sinden, Felicity Kendall, Joan Collins, Gareth Hunt, Joanna Lumley and many others.

In all 1981 has been a year to remember for ASBAH and while people have been talking about a lot of gloom and doom, we have been most fortunate in having gone from strength to strength. We therefore, are looking forward to a very happy and prosperous new year and as always I would like to wish you the same.

JUDY KAY



Mr Ron Fisher, Mr Barry Cryer and Miss Judy Kay as The Dickinson Robinson Stationery Group presents ASBAH with £5,000.

LINK INDEX—Issues 66–77

Below is an Index of some of the major articles which appeared in LINK during 1980 and 1981. Back numbers are available from National Office.

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WITH THE growth of international travel opportunities for disabled people and because expense can often be a major problem, many disabled visitors to Britain are looking for homestay accommodation. This applies in particular to disabled young people from Europe wanting to spend time in the UK, often to practise English, and there is increasing interest from the USA.

The major problem is linking prospective visitors with possible hosts and the PHAB (Physically Handicapped and Able Bodied) International Advisory Group, which links a number of voluntary organisations and those involved in international travel support services, is now preparing a list of

Visitors need friendly homes

hosts who would be prepared to receive disabled visitors.

Some of the visitors might be able to offer limited help in the home or offer possibilities of a return 'exchange' visit, others might require specialist help or look for hosts who have previous experience of their particular disability and there will be those who are much more independent and, depending upon their disability, will cope with stairs and other limitations often imposed by small houses in the UK.

At this stage the important factor is to gather the right information such as rooms available, possible length of stay, finance (if any) and the facilities offered, such as access in the house or knowledge of disability. PHAB stress, however, that the *willingness* to accommodate a disabled visitor may be much more important than specialist knowledge or a single storey house.

Those interested in exploring the possibility of providing accommodation or requiring further information should contact Terry Thompson, PHAB International, 42 Devonshire Street, London W1N 1LN. Telephone: 01-637 7475.

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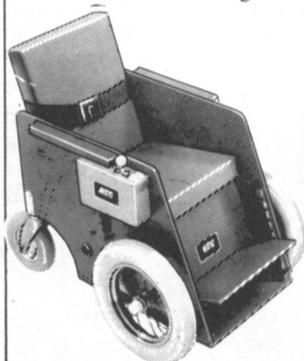
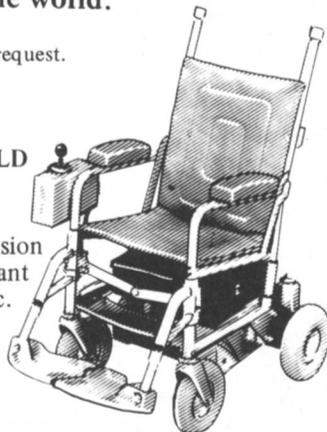
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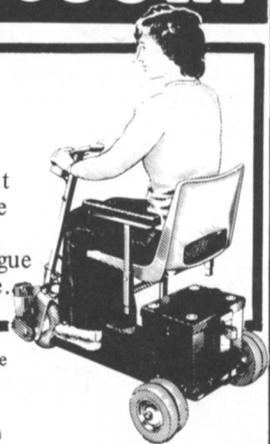


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Your Child with Hydrocephalus, by J. Lorber, MD, FRCP 35p

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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, 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).

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

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