Link

Association for Spina Bifida and Hydrocephalus/ASBAH

January/February 1986

30p

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Association for Spina Bifida and Hydrocephalus (ASBAH)

22 Upper Woburn Place, London WC1H 0EP

Registered Charity No. 249338 **TEL: 01-388 1382/5**

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

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ASBAH Publications

All available from National Office.
Cheques payable to 'ASBAH'

Children with Spina Bifida at School (1985) *Ed. P. Henderson*	95p
Young People with Spina Bifida and/or Hydrocephalus — Learning & Development (1985) *Leonie Holgate*	£1.60p
The Handwriting of Spina Bifida Children (1979) *Joan Cambridge, Eliz. M. Anderson*	£1.60p
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Research reports

The Further Education and Vocational Training of Young People with Spina Bifida and Hydrocephalus *Hazel Benner (1984)*	£3.00pp

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Magazines

LIFT — for members of LIFT (young ASBAH)	Free
Causeway — *for contributors to ASBAH's work*	Free

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UK	£3.30p
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Air Mail	£10.80p

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* *Except in the case of LINK all the above prices apply in the UK only. Overseas rates on request.*

Editor's Note

It is good to be able to start on a positive note. In the Sept./Oct. issue of LINK we highlighted the problems of a number of families living in the North. Now, on page 4, we can report that things have taken a distinct turn for the better.

Much of what is now happening was obviously in train before LINK went North but the article did serve to bring out the frustration of the people involved. Perhaps even more importantly the work now in hand demonstrates the importance of openness and good communication all round.

Meeting the needs of the handicapped should be, and is on this occasion, a team effort involving the individual and family, the local authority and, when appropriate, ASBAH.

LINK started its life as a magazine primarily for parents struggling with the task of bringing up spina bifida and hydrocephalic children. Some people, it seems, still think of it in that way.

In reality LINK has broadened out and now carries much that would be of interest to young people as they grow up and make their way in life.

So, if you are the kind of family in which LINK is for parents only, please pass it around. We want it to be a magazine for all the family and if we are failing we would like to know why.

Sue Gearing, Editor

On the INSIDE

MAIN FEATURES

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COVER PICTURE

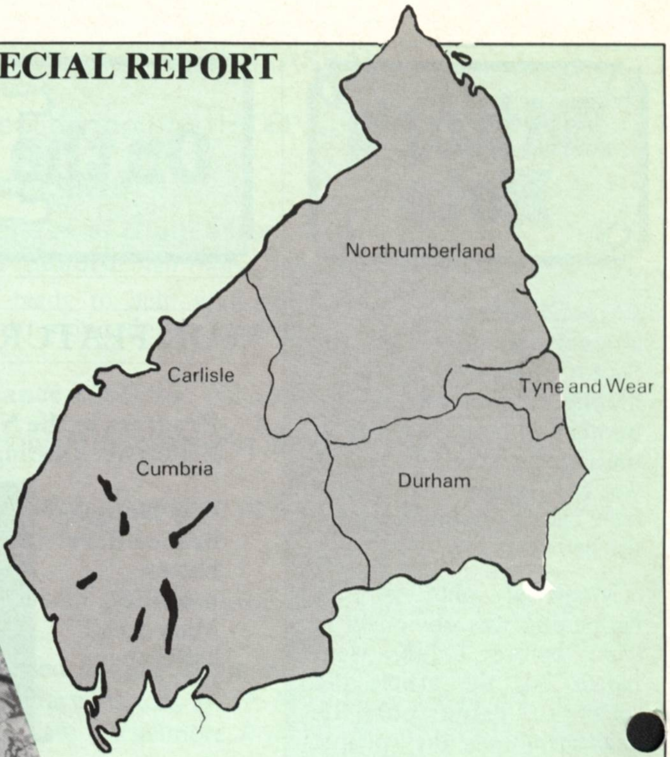
Della Skidmore and David Clift looking radiant at their wedding in the Summer — we thought a picture like this would chase away the winter blues! Della who has spina bifida and comes from Chiddingfold in Surrey was wearing a fairytale gown made by her mother and to complete the allusion the couple left the church in a horse-drawn carriage. By all accounts it was a magnificent occasion. The couple are hoping for good news this year — a home of their own. They wish to live in Chiddingfold village near Della's family, and Waverley Borough Council has promised to help as soon as something becomes available.
Photo: County Border Times.

Link is published by ASBAH (The Association for Spina Bifida and Hydrocephalus)

Contributions to LINK by way of letters, news, photographs, articles and opinions are warmly welcomed. The closing date for the next issue is December 5. Send to the Editor at National Office.

LINK SPECIAL REPORT

Goodbye to all this. Adaptations will bring a room of his own, and he need no longer sleep in the kitchen.



Good news from the North

THINGS are picking up for the families featured in LINK's recent article on the North of England. The Director of Social Services for Cumbria has replied at length to ASBAH, and in Cumbria, and elsewhere, there are clear signs of improvement.

The frustration of the families involved was real enough, but so too, it seems, were the problems faced by the social services. They had not 'packed up and gone away' even if that is how it sometimes appeared.

Take, for example, the position of the North West family whose teenage son, severely disabled with spina bifida and hydrocephalus, returned home after major surgery and had to sleep on the kitchen floor.

Plans have now been agreed for the family home to be adapted. The family will receive a 100 per cent grant and ASBAH will help out with the furnishing and fittings.

It appears things were heading in this direction when LINK's first article was published. But the route had proved difficult.

The family has written to LINK saying: "We did not buy our house against council advice. We would still be in a council-owned bungalow if we had been able to get something done about dampness. Our handicapped son's bed went green and mouldy and so did clothes in the wardrobe". The bathroom was on the ground floor, not upstairs as reported in LINK.

Eventually the family moved into their present home not as their first choice, but because they thought they could afford it. However it does appear that the social services were not consulted in advance about the move.

The situation in the house was aggravated beyond measure by the son's deteriorating condition, further major surgery and the need for constant care. Specific plans for modifying the house failed to meet building regulations, a problem which took a year to resolve.

The family with the non-working shower has had it reassessed. It looks as if an alternative way of heating the water will have to be installed.

The young mother from the North West who had problems with her kitchen and cooker is also much happier. A new cooker has been installed. The social services are to pay half the cost, with ASBAH meeting the other half. Kay is being asked to cover the cost of the fitting.

There is also some good news from the youngster in the North West who could not go to the neighbourhood secondary school but was offered a place at another ordinary school, one designated as suitable for the disabled. She did not go to the local school, but she is happy at her new school.

Each of these cases involved a tangle of human needs and emotions. Each in their own way presented special problems for the social services and other local authority departments. At this stage a blow by blow account of what went on is not possible, nor would it serve any useful purpose, but one thing does seem to emerge in most cases — more effective communication would have helped.

Life at Salters Lane

IT IS unfortunate that you chose to mention by name only two of the ten special schools for the Physically Handicapped in the region "It's a hard struggle for families in the North" (LINK Sept./Oct. 1985). If these omissions relate to the label 'good special schools' then I would wish to know by what criteria and by whom such judgments were made?

Comparisons are always rather invidious in that special school buildings, staffing ratios, resources and above all the range of individual children's problems all differ to a considerable extent between schools locally and nationally. Indeed for these reasons H.M. Inspectors of Schools rarely, if ever, use adjectives such as 'good'. All schools have their strengths and weaknesses.

I should like to point out that at Salters Lane School, Darlington, teachers and welfare assistants are part of a multi-disciplinary team which includes doctors, physio, speech and occupational therapists, nurse, educational psychologist, social worker, dietician and specialist careers officer. Any of these professionals can and do work with children during the school day.

This co-operation reflects our belief that Independence Training is a programme which a child follows right through the special school. This embraces maths, English and science for real-life situations, social and environmental studies, self-care skills including craft and home economics and a full programme of appropriate sport. Greater detail is given in the School's brochure, available to all parents and prospective pupils. There is an active Parents and Friends Association.

Finally, it is our policy to work closely with organisations such s ASBAH. Sandra Wheatley has visited the school on several occasions and is always welcome. Indeed in every case where a child has been nominated to attend an ASBAH Independence Course, the LEA, Durham County Council has sponsored them. It seems ironic that one of our pupils Samantha Nicholson is actually pictured in LINK (Sept./Oct.) as having participated in the Great North Run and having won two events at Stoke Mandeville. All training for the latter was done at this establishment.

I hope the above will allay any fears parents may have about the lack of mention of their children's schools.

R. T. WATSON
Head teacher, Salters Lane School

Kay, with her daughter and mother looking very pleased now that she can use her kitchen again to the full.

Why we need more help

I WOULD like to tell you my story and why I feel that there should be more help for families in the North of England.

My son, Lee, is now nearly eight years old and he was born with hydrocephalus. At that time I knew nothing of Spina Bifida or the other ailments that went with it. The hospital told me nothing except that it had happened and I wasn't alone.

After many operations and a very long stay in hospital I eventually got my son home, but that is where my problems started. Neither the health visitor, nor the hospital could tell us why Lee cried so much and was slow in learning. Then a student doctor noticed his valve was blocked. We didn't realise that this would happen.

After yet another operation his crying still persisted and he was sick every day. At three years we started him at a day nursery, the helpers there kept asking if there was something wrong. We had to say no as the hospital had given him a clean bill of health.

School started when he was four years old, and the same problems continued.

Over the years constant worry about Lee had started to tell on me, and one day in March 1983, after another phone call from the school, something inside me snapped.

I told the doctor that I couldn't go on. I was going to take Lee home and smother him and take my own life as well, that was how depressed I was.

The doctor arranged for Lee to be taken into hospital straight away. It became clear they had taken Lee away from me for his own protection.

In desperation I got in touch with the NSPCC and told them about my plight. I knew I had a problem.

The NSPCC were marvellous.

Within the week it was found that Lee had a hiatus hernia, and many other internal problems which he had had since birth. The operation was successful. Life for a while was wonderful.

Back at school however Lee's behaviour problems started again. We got back on to the NSPCC and this is where we had our first meeting with Sandra Wheatley.

Since then I have not looked back. If I had had a Fieldworker seven years ago, I wouldn't have had to go through all the heartbreak.

MRS CORAL WILLINS
Newcastle Upon Tyne

C Olds using the new Roy Douglas brace. It is normally worn under clothes.

A youngster puts the brace to the test.

New brace offers better mobility

DID you see the TV programme showing PC Philip Olds and children with spina bifida walking round a toy shop in a new brace designed in America?

I am sure that most of you have heard of PC Olds, the policeman who was shot and paralysed from the waist down.

The BBC have been running a series of documentaries about PC Old's progress and in the most recent programme they showed him walking in a special brace designed by Roy Douglas, and his colleagues. PC Olds is also a "guinea pig" for a team of researchers who are working on the electrical stimulation of paralysed muscles. Similar research is being carried out in this country but I want to concentrate on the Roy Douglas brace (Reciprocal Gait Orthosis). It is particularly exciting as it was initially designed for youngsters with spina bifida. Young people in Britain can now benefit from this advance in technology.

What are the problems with traditional calipers?

The traditional hip-knee-foot-ankle calipers, with which I am sure you are familiar, were designed to provide the person who could not control the muscles around the hips, with the means to walk, with the additional help of crutches. Walking in this way requires tremendous amounts of energy and the user may have to rely heavily on his upper limbs to support his body weight and propel himself forwards. Usually, when small children are first taught to walk in calipers, they are told to put one foot in front of the other ie foot – stick – foot – stick . . . (This is called a reciprocal gait).

As the child grows older and heavier, walking becomes more stenuous. Many young people find it increasingly difficult to walk placing one foot in front of the other. As calipers are often not rigid enough to keep the legs apart, the thigh sections may knock together impeding walking and often one leg gets left behind and a great deal of effort is required to drag this limb forwards. Inevitably, many people only stride forwards with one foot and drag the other.

Often to conserve energy and get about faster, many people adopt a "swing through" gait, ie you take the weight on your arms and swing both legs forwards together. Sticks – swing – sticks – swing.

Unfortunately, this method of walking can also be so strenuous and slow in comparison with other young people, that the user may opt to use a wheelchair to get around, both in and outdoors.

Why is the Roy Douglas brace different?

The objective of this new brace is to make walking much easier and less strenuous. The secret of its success is mainly due to the hip joints.

They are designed in such a way that when one leg is stretched forwards, it tends to force the other hip joint into extension. Likewise, when the person's weight is transferred to the other foot, the opposite leg swings readily forwards.

To see how these braces work, it is possible to "walk" them across a room, without anybody being in them, by simply transferring weight from one side to the other. In this way the brace automatically swings one leg in front of the other.

The overall result is a lightweight brace that offers improved cosmetic appearance. Moulded plastic is used instead of metal pelvic and thigh bands. The plastic shells secure the legs with velcro straps. Caliper sockets are not required as the plastic lower sections are designed to fit into ordinary shoes.

Recently, at the invitation of the brace manufacturers, Camp Ltd, I visited the Channel Islands to see it "in action". I stayed with a family in Guernsey whose son uses this brace. His walking is excellent and initial signs indicate that the brace and similar appliances designed on the same principles will bring braced walking into the 1980s.

Some Orthopaedic Consultants are prescribing these braces in the UK so if you want more information, please contact:— Mary Small, National Office or Camp Ltd (Southern Div.), Portfield Industrial Estate, Neville Shute Road, Portsmouth PO3 5RL. Tel: (0705) 697411.

Who's likely to benefit?

The Reciprocating Gait Orthosis has been used by children with spina bifida in the USA who would otherwise be unable to walk, but who possess sufficient upper limb strength to use crutches and maintain their balance. Obviously, if the child has sufficient hip strength to maintain an erect position and advance the limbs one leg at a time, some lesser form of orthotic management should be considered.

This brace is not recommended if severe irreducible contractures are present that prevent establishing normal alignment, in the case of obesity or for those who have poor upper limb strength. Adults using this brace can expect to need a wheelchair for mobility outside the home.

Self-service petrol: is it driving you mad?

Illustration by Cath Jackson, reproduced with permission of Consumer Voice.

At a time when more and more disabled people are enjoying the independence of driving, they are being threatened by lack of access to the very fuel that makes driving possible.

Self-service petrol stations have mushroomed in the past 10 years, from one in 10 to more than one in three. Most of them make it virtually impossible for a disabled driver to serve himself and pay. It can mean a lonely wait on a garage forecourt praying for an able-bodied motorist to offer help. Neither is there any joy or chance of help from the assistant ensconced in his glass kiosk. Safety rules say he mustn't leave his post!

Josy Cichockyj who has spina bifida is the information officer for D.I.A.L. in Huddersfield. She relies on her car to get to work and to provide her with social independence. She is just one of thousands of disabled drivers who feel threatened by and helpless about the present situation.

"The other evening, I was out in my car with my sister. She put the petrol in for me, and then the time came for me to pay — by credit card. I couldn't get into the office and the assistant told my sister that I couldn't sign the cheque outside — she must be able to see me. She could actually have seen me through the window, but no, it took a long argument before she finally and reluctantly agreed to come out for me to sign. It was ridiculous and frustrating."

Improvements

Some improvements which have been suggested include: lower, lighter-weight petrol guns, petrol pumps installed flush with the ground — not on plinths, ramps up to cash booths or a separate booth for disabled customers, more stations with attendants to help the disabled during certain hours and a map and directory indicating manned stations or those where help is on hand.

Consumer Voice the journal of the National Consumer Council, has taken up the campaign for improvements and has discovered that of all the oil companies, Esso alone has so far done anything positive — for the past two years is has published a free booklet listing its petrol stations which have an attendant available to help disabled motorists. The list runs to only a few 100 sites out of 3,000 bearing the Esso name because Esso owns and controls only 1,000 of the total number of sites — but it is, neverless, a useful aid.

Ramps

Other oil companies when approached and told about disabled people's anxieties, said they should investigate the matter, and Mobil announced recently that ramps are to be installed at its 300 company owned sites.

A project by the government in the euphoria of 1981 International Year of Disabled People — an attempt by the Department of Transport's Transport Policy Review Unit to produce a directory of all UK petrol stations offering special assistance and service — has died a death. Only Esso has taken any sort of step forward. Everyone seems to be in favour of action, but none is willing to take the initiative and the government hasn't been able to follow through with its initial idea.

More and more pressure from disabled people might persuade the companies and the government to act, not only to make stations more accessible but also to produce a directory, so please why don't you let us know your views and experiences and we can add our combined voice to the campaign.

We need more fuel for the campaign for more accessible fuel!

Sue Gearing, LINK Editor

Workshops on Sexuality

A unique opportunity is offered to 30 people with physical disabilities to attend residential workshops on sexuality, all expenses paid. These are to take place in Spring 1986 in Bournemouth (March 3-6) in Cork (March 11-14) and in Manchester (March 24-27)

They are part of a research project undertaken on behalf of the World Health Organisation by the Education Unit of the Family Planning Association. The role of the WHO is to make recommendations on all aspects of health (and this includes sexuality) to governments, health professionals, planners and administrators. The WHO recognises that people with physical disabilities frequently experience difficulties with sexual relationships, and that these might be due to lack of information, lack of understanding by others and inadequate services.

It wants to make recommendations that will stand a chance of being noticed and implemented, so these need to be based on the reality of people's lives — rather than the assumptions of professionals and researchers. Hence the workshops.

Each workshop will be for 10 people of different ages — men and women — with varying levels of disability: people who live at home or in residential institutions. Each will last for 3-4 days and will be run by experienced group leaders.

It is envisaged that the workshop will fall into two parts. The first will give an opportunity for participants to consider their own personal experiences and the factors affecting their sexuality and relationships. As usually happens when people discuss issues like this in a safe group it is likely that participants will want to consider what they can do for themselves in the future, individually or with the support of others in the group.

The next stage will be to produce the report. The participants, group leaders and study director will consider the implications that can be drawn from the earlier discussions, and draw up recommendations.

People who are interested in applying for these workshops should contact as soon as possible Mary Porter, FPA Centre, 8 Fairfields Road, Basingstoke, Hants, RG21 3DR or Joyce Rosser, FPA Education Unit, 01-631 0555.

Letters

AS A regular reader of LINK I was most interested in the letter sent by Kim Egan from Bristol (Nov. LINK).

As I collect for 17 charities which includes ASBAH I heartily agree with her. By all means let the ASBAH people be seen on our streets. Claiming to have a vast experience of collecting for charity, I know the general public love to see these 'great' people putting on such a brave show as they do. Their hearts go out to them and this affects their pockets too. So keep up the good work. . . .

Valentine Card, Chelmsford, Essex.

New chair to be assessed

THE VESSA SPRINT wheelchair has been added to the DHSS range but will be supplied only on medical recommendation and will be carefully monitored initially because the chair has not yet been proved in general service. The medical and technical staff of the DHSS Wheelchair Service will liaise with the user to confirm adequate assessment and note the medical reasons for the recommendation in preference to more standard wheelchairs. Adequate training for the user has to be arranged for this new chair, especially for anyone not used to a comparable model.

Local Association
Round-up

A knockout! A large cheque, by any standards, for £4,000, being presented by Wing Commander R. Dixon of RAF Sealand to the Chairman of Chester Local Association, James McMaster. The money was raised from Its a Knockout Competition (as mentioned in the la[illegible] LINK). Special credit goes to Clive Laurence (back row third from left). Clive, who works in a civilian capacity at RAF Sealand, organises fund raising events for Chester Association ye[illegible] in, year out and altogether has raised over £10,000 during the last ten years.

Wessex

TINA WALTER from Wessex ASBAH has written about her most memorable event of last year:

"I went to London to Hyde Park to raise money for the PHAB. We joined a sponsored 10-mile mini-marathon for wheelchair users and walkers.

"I had to get up at 5.30 am. I was picked up by mini-bus. There were twelve of us all cramped in together, and I did not enjoy the journey very much.

"When we arrived in London at 11 am, there were about 2,000 people all milling about the Park. . . .

"Jimmy Saville cut the tape for the start of the race, a band played and we set off. One of the helpers came with me around the Serpentine giving me assistance when I got tired. We went around five times.

"It was very pretty. There were ducks on the water and lots of statues as well as the people in front of me to look at.

"Jimmy Saville walked with me for a while. We chatted and he liked my new leather gloves!

"It took about four hours. It was very hot and I got sunburnt. I was aching from head to foot, but I had enjoyed it. . . .

"The next weekend I had some lovely surprises — a poster saying 'Congratulations' and a lovely big sponge cake which said 'Well Done Tina' in pink icing. It was delicious. I raised £83 for my local club."

Later, Tina and three other members of Weymouth PHAB were invited to London to present a cheque to Jimmy Saville, and travelled up by train.

"We arrived at Waterloo station and had to hire a taxi to the hotel. Debbie, our leader went in to get some help and a man with a top hat and tails opened the door and helped us in. It was packed inside with very tall and important people. I felt small and untidy. A large buffet was laid on.

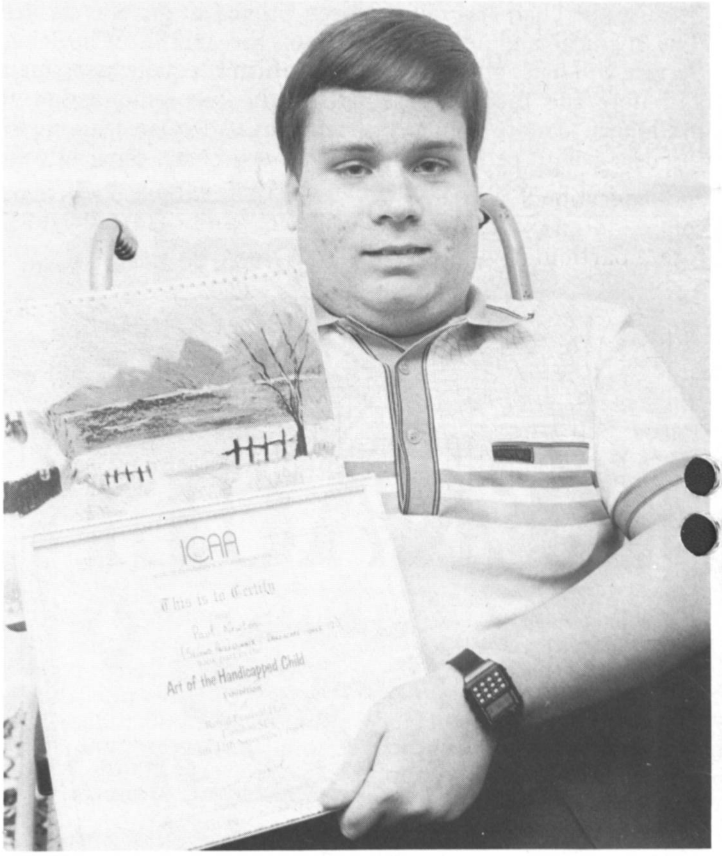
"We were called forward to meet Jimmy Saville. He chatted to us and then he gave me and Tracey a kiss. Jimmy asked everyone to give us a round of applause as we had travelled the furthest.

"We left the hotel at about 10 o'clock. I hailed a taxi and we piled in with difficulty. Our train left about 11 pm.

It was an awful journey because it was the Mail train. It was dirty and bumpy stopping at every little station. I tried to sleep but it was impossible. We all crawled out at Weymouth at 3.40 am.

"I was shattered but very happy as this was my first experience of travelling by train without my parents' help. Also it was one of my ambitions to meet Jimmy Saville."

LINK WANTS TO HEAR FROM YOUR LOCAL ASSOCIATION



Young master. Twelve-year-old Paul Newton of Pocklington Court, Padgate, Cheshire, who was joint runner up in the over 12s section of an 'Art for the Handicapped Child' competition organised by the Invalid Children's Aid Association. Prizes were presented by TV personality Matthew Kelly. The paintings were on display at the Festival Hall in London before going on tour, and then to Tokyo. It has been an exciting time for Paul who has spina bifida. Among other things he was interviewed on BBC Breakfast Time.

Photo: Cheshire County Newspapers.

Local Association Round-up

Sussex

WORK has started on converting a large 1930s house in Grand Avenue, on the outskirts of Worthing, into nine bedsits. This long awaited project has been financed by Downland Housing Association, and Sussex ASBAH is furnishing and equipping the house. It is hoped that the first resident will be able to move in during May. The house will take up to nine young people, living in their own bedsits, who will be able to stay there for one or two years, learning how to be completely independent, and how to manage their money, shopping, catering, coping with personal care, etc. They will have the help of a resident warden.

Hull

THIS association is planning and educational trip to the continent and were, therefore, particularly pleased with the results of a sponsored swim by adults and children that raised £1,425. Hull city Football Club player Peter Skipper presented certificates to over 50 children and adults who had taken part. He was pictured in the local press with Jennifer Hall, age 7, who has spina bifida and completed 100 lengths of the swimming pool.

Somerset

A RECENT donation of £370 to this association has been earmarked for car adaptations for the young people who are keen to learn to drive and have their own cars. It was raised from a sponsored walk by Mr Terence Cox. Altogether the walk raised over £1,000 and the money was divided between Somerset Association, Leukaemia research and the Diabetic Association. Mr Cox presented the money at a skittles evening in the Somerset village of Mark.

Bright spot. Members and friends of Mansfield, Worksop and District ASBAH pictured on arrival at Blackpool after a 150-mile trans-Pennine motorway trip on the 'Handicruiser', Nottinghamshire County Council's specially adapted Bova luxury coach, complete with wheelchair ramp and spaces. The 32-strong party rounded off their sunny day out with an hour-long nose-to-tail drive along the seafront to view the world famous Blackpool Illuminations.
Photo: Mansfield Chronicle Advertiser.

Marathon man Gordon Gibson, wet and tired, but delighted with his medal to prove that he has just completed the Coventry marathon for the first time. He raised £110 for ASBAH. Gordon's niece, Mrs Janice Short, has an 11-month baby boy with spina bifida. "Having him has created a new lease of life in our family" she wrote in her letter to LINK, and sent this picture of Gordon just to prove it.

ASBAH Conference

5-7 September
Sheffield University

A DATE for your diary this year! ASBAH is holding its bi-annual Conference in September in Sheffield and combining it with the Annual Meeting (which has been held in London in the past). It should be an enjoyable weekend and ASBAH hopes that all local associations will be represented.

FAREWELL to ASBAH's Appeals Director, Judy Kay, and her Assistant, Ann Gosling. Both have been with ASBAH for seven years and achieved a great deal in the field of fund-raising and publicity. They started in the New Year on a campaign for the Chest/Heart and Stroke Association.

DUE TO the demand for back numbers of LINK we are sorry that no more are available. However, if you would like a particular article photocopied we will be happy to do this. Contact the Information Officer, Beverley Holland.

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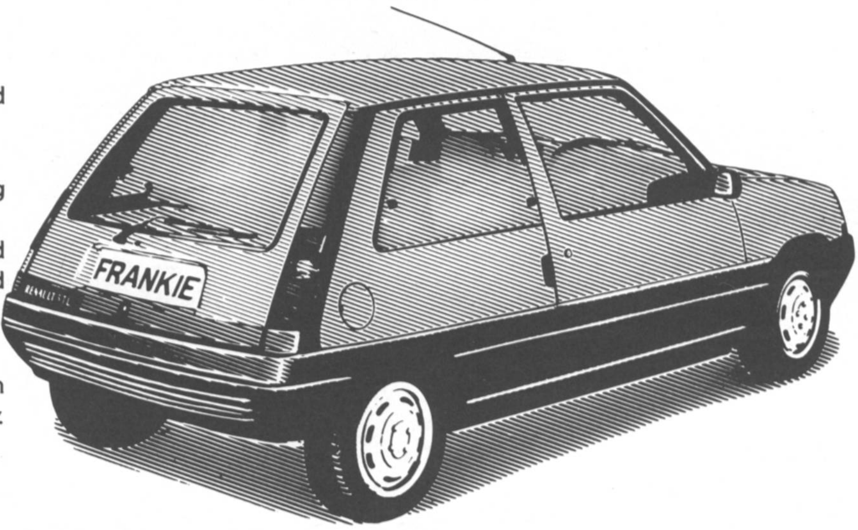

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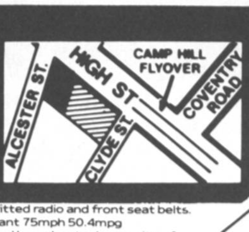

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Bodytalk

Hydrocephalus caused by Haemorrhage in the Premature Infant

by Gillian R Stellman, Department of Psychology, and Carys M Bannister, Department of Neurosurgery — both at Booth Hall Children's Hospital, Manchester.

ALMOST daily in the media we hear of new and wondrous advances in modern medicine.

Of great interest to LINK readers is likely to be the recent progress made in the care of the premature baby in Special Care Baby Units. In them an infant born so prematurely that up to a few years ago his chance of survival was very slim, can now be cared for, and he has an excellent prospect of becoming a strong and healthy baby.

However, new technology may, as well as bringing about wonders, also create new problems. An example of this is the infant who develops hydrocephalus as a result of complications associated with being born far too early.

An infant born after only 36 weeks of pregnancy is far more vulnerable than a full term one since many parts of his body have not yet matured; the brain for instance is still in a very active stage of development. Of particular importance is an area of rapidly multiplying cells which lies just beneath the lining of the ventricles (the chambers of the fluid system of the brain). Because so much activity is going on in this area, it has a plentiful blood supply. Its blood vessels are very fragile and can easily burst if the baby suffers too large a swing in his blood pressure or in the amount of fluid in his system. In the mother's womb neither of these things happen, but they can occur as a result of complications that may follow an infant being born very prematurely. If these complications do occur then these babies are at risk of developing a haemorrhage from rupture of the fragile vessels. This can lead to a blood clot developing, which in some cases is big enough to break through the wall of the ventricle. If the clot blocks the free flow of fluid through the ventricles, the baby will develop hydrocephalus.

Careful observations

Most Special Care Baby Units are equipped with ultrasound scanners which can detect these haemorrhages in the babies brains and see if they have extended into the ventricles. Therefore babies considered to be at risk are often scanned frequently. If they are found to have had a haemorrhage, they are observed especially carefully to detect any changes in their condition which might indicate that they are developing hydrocephalus. A baby with hydrocephalus will very probably have a larger head than expected for his size and age, the increase in its size will be too rapid, and the soft spot will feel tense. The veins on the forehead and scalp are often prominent. All these signs will become more evident unless the hydrocephalus is treated. Ultrasound scans may be used to confirm that hydrocephalus is present.

Frequently when premature babies first develop hydrocephalus they are too tiny at that time to be considered for the insertion of a shunt system. The simplest way to control their hydrocephalus is to drain off some of the fluid by passing a needle into the ventricles through the soft spot in the head once a day or so, or as often as necessary. This procedure is continued until the baby no longer has signs of hydrocephalus, or has reached a weight of 2kg.

If there is still evidence that hydrocephalus is present at that time the baby is now usually big and fit enough to be transferred to a Neurosurgical Unit where an operation can be carried out to insert a shunt system to drain fluid from the ventricles continuously into either the heart or more commonly the abdominal cavity.

It has been our experience that despite the fact that all the premature infants have received similar care and attention after birth, they show a great range of variations in their later development; some have done extremely well and are going to normal school, while others have problems of differing severity varying from the relatively mild to severe multiple handicaps.

Study of 40 babies

In Manchester we have studied more than 40 babies born prematurely who have developed hydrocephalus after having a haemorrhage. We set out to discover what factors might be causing the severe developmental problems in some of these babies. How premature a baby was at birth, was not by itself a good predictive factor, nor was the baby's weight at birth; we found that more mature, heavier babies were just as likely as their less mature, lighter fellows to have severe problems when they grew older.

Many very premature babies immediately after birth require mechanical assistance to breathe, and some of them have remained on the machines for a comparatively long time. We found that whilst being on a mechanical ventilator did not increase the likelihood of a baby having developmental or physical problems, there was an association with the length of time they needed mechanical help; children with the worst handicaps were likely to have spent a significantly longer time on a mechanical ventilator than those with minor problems.

History of the haemorrhage

Of great importance and interest to our investigation was the history of the haemorrhage, and the course and treatment of the resulting hydrocephalus. As previously stated "at risk" babies tend to have frequent ultrasound scans, and so a fairly accurate assessment was possible of when each baby had

Continued on Page 15

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Continued from Page 13

suffered his haemorrhage.

We found that children with severe developmental problems were likely to have had their haemorrhages later after birth than the less disabled ones. The reason for this may be that it takes a bigger swing of the blood pressure or a greater problem with fluid balance to burst the stronger, better developed blood vessels of the older infant. The resultant bleeding is more severe than that which usually occurs in younger infants, and it often causes considerable damage to the surrounding brain. Unexpectedly it was found that having more than one haemorrhage did not seem to increase the chances of the baby developing a severe handicap.

The way the baby's hydrocephalus was treated did not seem to significantly effect his eventual development. Almost all the babies in series we investigated had fluid drained from the ventricles before a shunt was eventually inserted. But how soon after the haemorrhage fluid withdrawal was started, how often it was carried out and for how long had no links with the baby's eventual handicap. It did not seem to be significant either how long it took the babies to reach the target weight of 2kg when their shunts were inserted, although most babies reached this weight at about the time they should have been born.

It was quite common for the babies to have experienced one or more of a number of serious illnesses including jaundice, septicaemia or severe bowel problems which might or might not have had to be treated by an operation. Chest infections, problems with the balance of the sugar levels in the blood and with the levels of trace elements in the body also occurred commonly. None of these, either alone or in combination, were shown to be linked to the degree of severity of the future handicap.

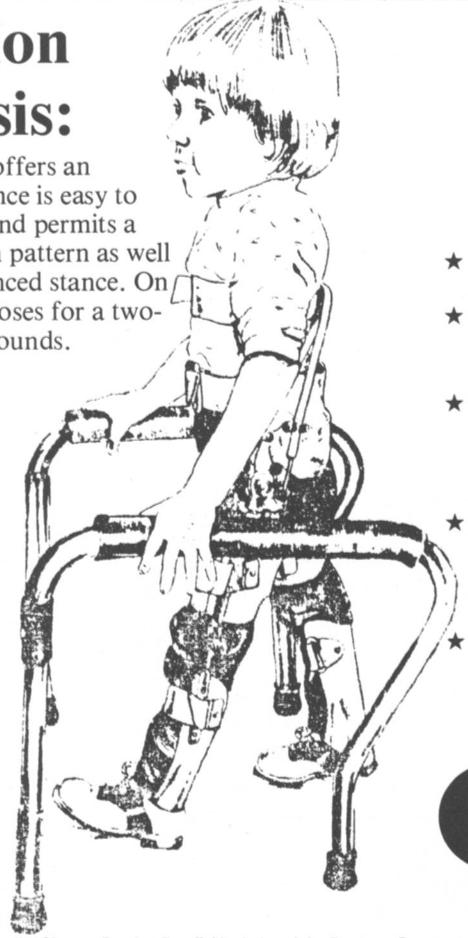
Head size

Many parents were worried about the size of their baby's head at the time of their shunt operation, and indeed many of the babies in our series had rather large heads. Not surprisingly, ultrasound or CT scan examination at the time of the shunt operation showed that there was a considerable variation in the size of their ventricles. However, ventricular size seemed to make little difference to how well the babies eventually developed.

The ultrasound and CT scans sometimes showed up other abnormalities in the brain; some babies had a cyst which was in communication with the ventricles. These cysts are caused by an extension of the original haemorrhage into the substance of the brain; after the resulting blood clot has dissolved away, a space is left which eventually communicates with the ventricles. The cysts occurred in as many babies who grew up without abnormalities as those who had severe problems.

Many different and complicated events affect premature babies who develop hydrocephalus after a haemorrhage. Our investigations have not positively indentified any factors or combination of factors which can be used to predict accurately how well these babies will eventually develop. About 40% of the babies we examined had a normal range of abilities when examined at 3, 4 or 5 years of age although many of them had been somewhat slow to sit, crawl or walk.

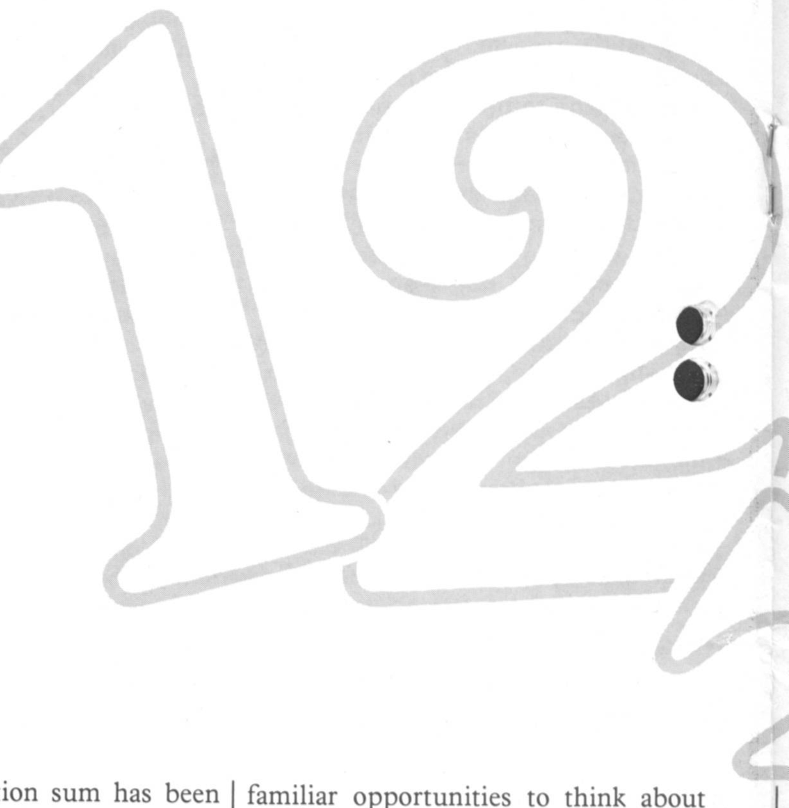
Further studies of greater numbers of children are needed before it will be possible to forecast accurately how well an individual new born premature infant is going to develop in the long term. What we know already is that in spite of having a haemorrhage and developing hydrocephalus which often requires prolonged treatment and a shunt operation, many of these babies will develop normally or have only minor disabilities.



THE SECOND in a series of articles for LINK by John Costello, a teacher, and father of a boy with spina bifida and hydrocephalus.

Putting 2 & 2

Numerac



Children with spina bifida, and particularly those with hydrocephalus, often appear to have special difficulties with number work at school. This can be worrying, because maths is usually thought to be an important school subject.

Most people believe that basic mathematical knowledge is necessary both in coping with everyday life and in finding a job. Yet at the same time many people have very little confidence in their own mathematical ability, and are quite happy to claim that they have never been any good at maths.

Recently people have started to talk about "numeracy". What does it mean?

Well, let's say that numeracy is the ability to think and work with numbers in a way that is useful in today's world. This does NOT mean setting out detailed arithmetical calculations neatly and accurately on paper. Twenty or thirty years ago, pencil and paper arithmetic may have been a useful skill. But we can be quite certain that this is a skill which our children are simply not going to use.

Consider for a moment some of the changes in daily life during the past twenty years. Calculators have become easily available, electronic petrol pumps have changed the way in which we buy petrol, and supermarket check-outs are quite different from old cash registers. These changes don't make maths less important. But it isn't being able to do the calculation which matters — the important thing is to understand how all this equipment is used, what the numbers mean and whether the "answer" on the machine is reasonable.

Traditional maths teaching in schools, particularly in some special schools, has often taken very little account of these ideas. For children who have special difficulties with maths, the approach has sometimes been to concentrate almost entirely on pencil and paper arithmetic. Calculations are broken down into simple steps, and taught painstakingly. The ability to set out properly a two-figure addition or subtraction sum has been seen as a major achievement.

This is silly, for two reasons.

- First, this particular aspect of maths can be enormously difficult for children with neurological and co-ordination problems. ASBAH's booklet *Children with Spina Bifida at School* mentions difficulties with "working sums" and with "identifying the correct digit on which to carry out computations".
- Secondly, even if children master these skills successfully, they are frequently unable to recognise any situations in which the skills can be used or to interpret the answer in terms of anything real. This laboriously learnt ability proves to be of no practical use to them.

What sort of number work is genuinely helpful? Perhaps most obviously useful is to practice simple mental arithmetic in context. "In context" means *not* saying "take 12 from 25" without giving this any meaning. It means taking advantage of familiar opportunities to think about numbers.

Most people learn to handle money in this way. We look at the money in our pockets and the price of things [illegible] shops before deciding what we can buy. We get quite clever at this, even with fairly big numbers: for example, we realise that the cost of 3 items at 95p each will be a little bit less than £3.

Other good contexts include distance and time: if we're going to make a journey of about 90 miles by car on a reasonably good road, we reckon that 2 hours ought to be enough time. If a television programme is advertised as starting at 7.40 and finishing at 8.25, we can fairly easily work out how long it lasts.

It is also important to become confident in using the technical devices which are commonly used for handling numbers. This means having a calculator and using it. It means understanding and using timing devices on video recorders, electric cookers and so on. It means looking at, and talking

2 together

acy for adult life

about car mileometers, gas and electricity meters and other measuring instruments.

If the opportunity arises, it is worthwhile operating petrol pumps or check-out tills and seeing how the numbers are displayed and what they mean. Increasingly, too, work with micro-computers is becoming more important.

Some people are afraid that encouraging children to use calculators will make them less able to do or to understand arithmetic. There is, however, no evidence that using calculators reduces children's skill, and some research suggests that children who use calculators become better at mental arithmetic.

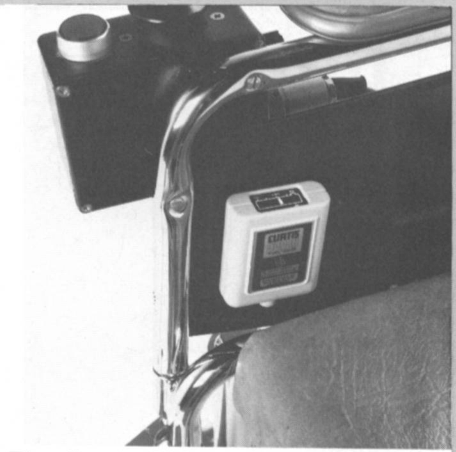
In its own way, the calculator is just as valuable as an aid to the handicapped as many more specialised devices. To suggest, as some people have, that children should not be allowed to use calculators unless they can do the calculations on paper is about as ridiculous as saying that you shouldn't be allowed to use a car to go shopping unless you can walk there anyway.

One sad aspect of difficulties with numbers is the way in which girls appear to be at a disadvantage. There is no real reason for this. Somehow, people expect boys to be better at maths than girls. Furthermore the increased use of computers and other technical aids seems less helpful to girls: an interest in such equipment is often considered more appropriate for boys.

We can also make life very difficult for disabled girls by emphasising traditional feminine values of neatness in work, appearance and behaviour, in which many girls are unlikely to excel. We have to be careful, too, that we do not respond differently to girls just because they're girls.

There is a temptation to say to a girl who provides good work in maths "You must have worked very hard and taken a lot of care" but to a boy "You obviously have ability in this subject". We interpret what we see according to what we expect.

Probably the best maths teaching is that which doesn't impose standard methods on children, but encourages them to find their own strategies for solving problems, in the way that works for them. In this respect, learning maths is like many other aspects of education for those with special needs. It is about developing a personal independence which enables one to cope with life's problems in whatever form they might appear.



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WE continually hear from young disabled people who only make limited use of their power chairs and pavement driven vehicles because they are afraid of running out of "juice" and being stranded.

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Another common problem powered chair users face, is not knowing at the end of each day how much power has been used. The tendency is to be cautious and put the battery on charge every evening. This continual charging can result in battery damage and ultimately shorten it's life.

Properly used, in conjunction with a battery in good condition, the 900W will avoid deep discharge and overcharging. It can extend the life of the battery by over 100%.

The 900W is compact, weather proof, durable and apparently easy to fit. It is stuck by an adhesive pad on to the side or arm of the wheelchair and has a unit to connect its wires to the battery terminal.

It is available by direct mail order from Curtis, and from selected wheelchair distributors at £49.50 plus VAT. Distributors may charge a fitting fee. State the name and model of your chair or vehicle as special connectors will have to be fitted at intervals down the wires length from the gauge to the battery so that the chair can still be dismantled or folded easily.

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Two of everything.

Coping with twins - both of whom have spina bifida and hydrocephalus

by their father Edward Evans of Randalstown in Co. Antrim

GAVIN and Ewart were born in the Mid-Ulster, Hospital Magherafelt, Co. Londonderry on February 24, 1975 by Caesarean section. I work in this hospital laboratory as a Scientific Officer.

Our elder boy is called Alwyn, and he was two years, four months when the twins were born.

It was a great shock to everyone as we had no reason to think anything was abnormal. We had been told in November that it was twins. No scans were carried out.

The twins were transferred to Royal lfast Hospital for Sick Children to be assessed. Gavin was sent back to agherafelt without surgery and little hope. However, he remained in the hospital for 18 months before coming home. Ewart had surgery on his back the day he was born and a shunt put in three weeks later and he came home after six weeks.

"We have experienced lots of problems over the last eleven years. Gavin has had some trouble with shunts. I forgot to mention that Gavin had a shunt after five months, a new one after one year and I think two more. Ewart had the same shunt for eight years but was never very well. He was very thin and prone to bouts of sickness and fever. When he was eight he developed shunt nephritis, so it was decided to remove the shunt as it had been colonised by bacteria, possibly for years. That was two years ago and thankfully he has not needed a replacement. We still keep an eye on him but it has been wonderful to see him so well and we just hope and pray that he does not need a shunt again. One shunt to worry about is bad enough, two is just too much!

Ewart

Ewart attends our local primary school and copes very well. He is very good at English and oral work and an excellent reader, but poor at maths. He is doubly incontinent and still wears pads. He walks quite well but had some surgery on one of his feet a few years back. He has a very independent nature and likes to be treated as a normal child. He understands that he is somewhat handicapped and hates the fact that he cannot use the toilet. Considering everything he accepts it all quite well.

Gavin

Gavin attends a special school ten miles from home. He goes in the school bus each day. He has no movement below the waist and spends most of his time in his wheelchair. Socially he is very bright and communicates very well. He takes great interest in everything around him. For the most time he is very happy. His school work is poor and his concentration very bad. He likes singing and music and enjoys the freedom of his electric car which allows him to go outside with the other kids who are good and kind to him.

Alwyn

As you can understand our home is pretty well geared up for the handicapped. We try to keep things as normal as possible especially for our eldest boy, Alwyn. He is the odd one out being able-bodied in a very handicapped family. He is a very sensitive child and a little insecure — you can imagine why!

The past ten years have not been easy for him, but he loves his brothers very much and is very good to Gavin. We just hope he grows up not too scathed from his unusual childhood.

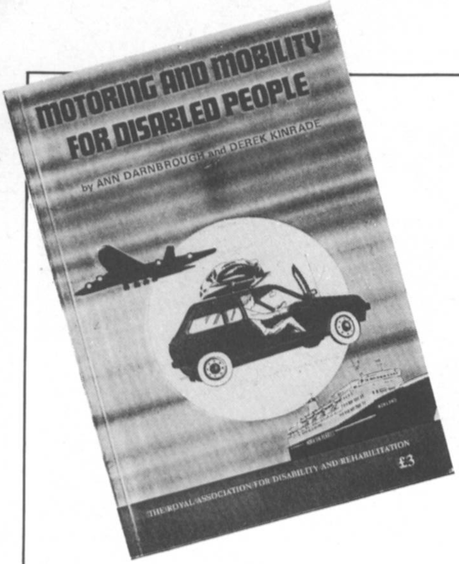
During the past three years my wife and I have been able to have a holiday away together on our own. The boys' aunt Elizabeth looks after them for us, and this is wonderful. We also try to go away for a family holiday — usually self-catering. We have been to Scotland, Wales and Southern Ireland and would like to venture a little farther as we feel this would be good for the boys, but we keep worrying about things going wrong when we are away.

We are both actively involved with ASBAH and get a lot of help from contact with other families in our area. We belong to the Antrim and District branch and meet once a month. At the moment I am Chairman. The boys love the outings and parties given by the branch.

We had to adapt our home some three years ago to suit our needs and we are again considering more work to give us more space and better access.

There always seems to be something happening. Life is very busy and we really have to work at keeping things on an even keel.

Reading Matter



Motoring and Mobility for Disabled People

by Ann Darnbrough and Derek Kinrade. Published by RADAR.

ALMOST anything to do with wheels and mobility comes under the spotlight in this revised edition, which is excellent value for money.

It looks not only at standard production cars, special purpose vehicles and conversions and accessories, but also all other aspects of motoring such as finance, insurance, licenses and parking.

It also covers Dial-a-Ride schemes, assessments, wheelchairs for adults, holiday motoring, and gives a list of useful books and organisations.

Available from RADAR, the Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400. Price £4 (post and packing paid).

A Celebration of Difference — a book by physically handicapped people.

Published by Bristol Broadsides.

RICHARD Gilling, who is disabled with cerebral palsy had the idea for this book several years ago. "I felt it was important to emphasise the abilities of people with physical disabilities. So much emphasis in the media is on the disability rather than the ability".

Thirteen different people with disabilities — many of whom have cerebral palsy — talk about their experiences, their lives, their disappointments and their achievements. The aim of the book is to make more people aware of the abilities, hopes, aspirations and needs of disabled people.

Available from: Bristol Broadsides, 108c Stokes Croft, Bristol BS1 3RU. Tel: 0272 40764. Price: £1.95 plus 40p post and packing.

Door-to-Door — A guide to transport for disabled people

Published by the Department of Transport.

THIS second edition of Door-to-Door should be available at the end of January.

It gives information about transport facilities and services for disabled people on all forms of public transport by land, sea and air. It also covers other, more specialised forms of transport for disabled people and gives details about buying and running a car and about entitlement to aids and financial benefits. It will be useful to anyone who is disabled or who works with disabled people as well as to transport operators and manufacturers: anyone, in fact, who is concerned with meeting the needs of disabled people. The first edition of the Guide, published in 1982, was a huge success selling nearly a million copies.

The Department are also producing a tape version of the Guide which will be available to organisations for the blind and individual blind people.

The Guide and the tape version will be available free of charge from Social Services departments/Social Work office Health Authorities, Libraries, Volunta Organisations or direct from Departme of Transport, Door-to-Door Guide, FREEPOST, Victoria Road, South Ruislip, Middlesex HA4 0NZ.

The invaluable ***Disability Rights Handbook*** has now been revised and covers the period November 1985-July 1986.
Price: £2.40 post free from Disability Alliance, 25 Denmark Street, London WC2H 8NJ. Tel: 01-240 0806.

REVIEW

Spina Bifida in South Wales — Can it be prevented?

by Nansi James. Published by University College of Swansea.

RECENT research into the prevention of spina bifida is summarised in this booklet, and progress made in South Wales where the incidence of spina bifida is twice the national average, is described.

Prevention may be secondary — by antenatal screening and diagnosis — or primary — by attacking the root causes of the condition. Much of the research into primary prevention has focused on the influence of dietary factors with the identification of a link between maternal malnutrition and the incidence of neural tube defects. A genetically vulnerable fetus may, at a critical point in its development, be affected by various environmental trigger factors. Faulty diet may be one, and various studies have demonstrated that the diets of women in social classes IV and V, in which the incidence of neural tube defects is comparatively high, are likely to be deficient in minerals and vitamins essential to the developing fetus.

The link with poverty is obvious (and worrying in view of the current recession) but the book also makes some interesting points about the influence of dietary habits acquired in childhood and about women's eating patterns. Metabolic factors may also be important and more information on this would have been welcome in the text.

Both dietary counselling and vitamin-supplementation of high-risk women appear to have reduced the incidence of recurring neural tube defects. The current well-publicised Medical Research Council research seeks to establish the efficacy of vitamin-supplementation and t determine which vitamins or folates are crucial.

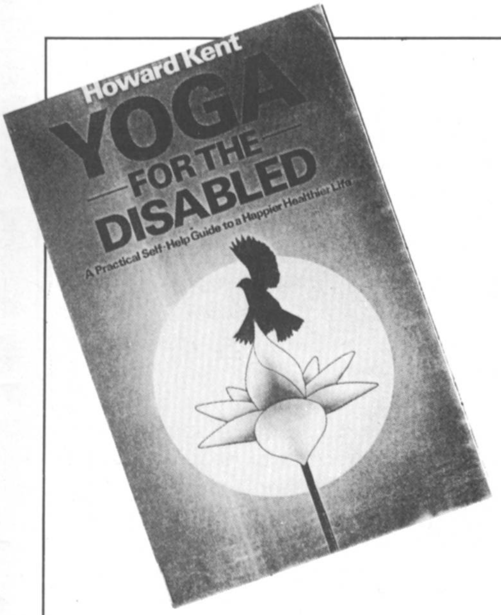
Strategies for future primary prevention are discussed including the setting up of preconceptual clinics, a programme of health education and supplementation of the diet of high-risk women.

This is a useful survey for those concerned with families at risk and for parents themselves willing to wade through a certain amount of technical data.

Angela Lansley,
ASBAH Fieldworker,
Liverpool.

Available from Publications Department, University College of Swansea, Singleton Park, Swansea, SA2 8PP. Price: £1.95 (post and packing paid).

Reading Matter



Howard Kent

YOGA FOR THE DISABLED

A Practical Self-Help Guide to a Happier Healthier Life

Yoga for the Disabled

by Howard Kent (Director of the Yoga for Health Foundation). Published by horsons.

THIS fairly wordy, but essentially aight-forward and clear explanation of the benefits of yoga would be an ideal first yoga book for anyone with a physical disability. (A suitable book to follow this would be Dr. Barbara Brosnan's *Yoga for Disabled People.*)

There are details of simple breathing exercises and postures most of which can be done from a wheelchair, although Mr Kent encourages the reader to get on to the floor wherever possible.

One Chapter is usefully given over to the correct posture for sitting in a wheelchair and suitable wheelchair exercises.

Available from large bookshops, price: £3.95 or from Thorsons Publishers Ltd., Denington Estate, Wellingborough, Northants NN8 2RQ. Add 50p p & p.

The Educational Implications of Disability

by J. Male and C. Thompson. Published by RADAR.

FOLLOWING the implementation of the Education Act 1981, more and more teachers in ordinary schools are asking questions about children with special needs and what they can do to smooth integration. This guide endeavours to answer teachers' questions.

It outlines 29 of the most common disabling conditions found among school children and explains how they are caused, difficulties children may have, and ways of overcoming them.

The guide is very easy to read, using non-medical language, and should help teachers understand the needs and abilities of children with disabilities. There are some useful appendices on the Education Act, and selected further reading suggestions.

Available from RADAR, 25 Mortimer Street, London W1N 8AB. Price: £2.50 plus 60p (post and packing paid).

Don't forget to send for a copy of ASBAH's new book for young people ***(Spina Bifida & You"*** reviewed in the last LINK.

Celebrity, Claire Rayner (one of ASBAH's new Vice-Presidents) launched the book in London in December. She felt that it could usefully be read by all young people, whether disabled or able-bodied. "It's a smashing book".

She hoped that libraries would stock it, and urged people to go to their local library and order a copy.

For details of ordering and prices see the inside front cover of this issue of LINK.

Newslines NEWSLINES Newslines

Eight young people look to the future: These young people with spina bifida and/or hydrocephalus are pupils from Coney Hill School and Nash House, in Hayes, Kent. Each is going on to, or is already on, a further training scheme. They are: (left to right) standing: Andrew Baker, Asra Jilani, Lee Buckenham, Nicholas Slater and Loraine Gordon; sitting: Daphne Mitchell, Jenny Moss and Neal Levack. Andrew and Asra are now on 'O' level courses at Orpington College, Nicholas is doing YTS training in carpentry, and Lee is at Hereward College doing a Business Studies Course. Loraine is hoping to move to a similar course at Colchester Technical College next year. Neal has gone back to the Isle of Wight to a Work Orientation Course. Jenny is on YTS training with Bexley Borough Council and Daphne is working temporarily in an optical instrument factory before going on to YTS Word Processing training. "Each is a lively, confident and capable young person whom we have been proud to have here and of whom other young people with spina bifida may like to hear" says Mrs D. E. Hobbs, Head Teacher.

• WORK has started on building a £1.2 million Regional Genetics Centre at the University Hospital of Wales in Cardiff. It will be one of the largest and most comprehensively equipped in the country.

The centre will provide a Welsh genetic disease treatment service, improve research into genetic malformation and treat genetic diseases such as spina bifida and muscular dystrophy. There will also be research laboratories for biochemical genetics and cyto genetics. Prof. Michael Lawrence's Department, and the Department of Medical Genetics headed by Prof. Peter Harper will be based in the new centre.

The Welsh Office has provided two thirds of the cost and voluntary organisations, including ASBAH, are also contributing. There is, however, estimated to be a shortfall of at least £200,000 at present.

• AN ACCESSIBLE public bus service — the Careline — will operate between major rail and coach stations in central London and Heathrow airport from early this year. It will run at hourly intervals stopping at Paddington, Euston, Kings Cross, Waterloo and Victoria, Victoria Coach Station and all Heathrow terminals. This much needed service will be operated by Alder Valley, a subsidiary of the National Bus Company, and has come about through the co-operation of National Bus, British Rail, London Regional Transport and the British Airports Authority.

• A BRITISH Telecom guide to equipment and services for disabled customers has been published. It was prepared by British Telecom's Action for Disabled Customers unit to assist British Telecom staff but it will also be of assistance to disablement organisations. The new emblem on the guide, two doves symbolizing freedom from handicap, has been painted by a disabled artist. It is the emblem of British Telecom's Action for Disabled Customers, a group launched in 1984 to identify the telecommunications needs of disabled people, and to co-ordinate and expand the range of services to them. Copies can be obtained from British Telecom Sales Offices.

• THE BRITISH Sports Association for the Disabled will host the first World Games for Disabled Youth in Nottingham in August and September this year. National Westminster Bank is putting up £125,000 sponsorship, and it is hoped that the Games will attract 400-500 competitors from 30 countries. After coaching sessions there will be competitions in four sections: for those with cerebral palsy, amputees, paraplegics and the blind.

• THE CO-OPERATION of children with spina bifida and/or hydrocephalus who are currently being integrated into mainstream schools, and of their parents, is being sought by Mrs Geraldine Walsh. She is hoping to undertake case studies of such children as part of her BA (Hons) degree at Avery Hill College. The studies will be confidential and everyone involved will remain anonymous. If you would like to help please contact: Mrs Geraldine Walsh, 202 Footscray Road, New Eltham, London SE9 2EL.

Now a little more help with the chip

BROADCASTING Support Services has set up an information and referral service for disabled people who want to know more about how micro technology can help them live more independent lives.

This Chip Enquiry Service is part of the support being provided to the BBC series on technology for disabled people 'With A Little Help From The Chip' (Producer: Anna Jackson). Viewers can write in with questions to a letter answering panel of specialists.

One of the problems people with disabilities sometimes have is making micro-aids work properly. Supplementing the letter answering panel will be a network of nearly 200 computer clubs, colleges and voluntary groups up and down the country. They have agreed to help enquirers in their area who need low level technical assistance, e.g. in connecting up equipment, or help with software writing, or even in developing a piece of hardware such as an electronic aid.

Other elements to BSS's service include some information pages on PRESTEL for use by viewers. These have been kindly donated by the Association of Computer Clubs. There will also be a free booklet giving much useful information and contacts. This is being published by the BBC.

With a Little Help from the Chip programmes are scheduled for repeat on Sunday mornings on BBC 1 (from March 16 this year): 'Christopher's Magic Cupboard . . . at 11.45 am; programmes on Communicating, Learning, Getting About, Working and Inventing . . . at 12.10 pm.

This may be subject to alteration so please check in Radio Times or the Daily Press.


Holds fast . . .


Peels apart easily

Charles Moore, Executive Director of John Grooms looks at the inadequate housing provisions for disabled people, and discusses the need to be prepared for living independently.

Home truths

ALL of us need a place in which to live and we all have our dream house. It may be a modern flat with all mod. cons. or a cottage in the country with roses growing round the door, but whatever our plans and dreams we would like to have a range of places to look at and, above all, a choice.

The range available to able-bodied people is limited only by what they can afford and what is available in the area where they want to live. It is not so for disabled people and even less for those who need to use a wheelchair for daily living.

Not only is there a shortage of suitable accommodation but disabled people are often on low income and, maybe, using all the monies they have to cope with personal care needs and getting around. Very little is left over and to buy a house would, for many, be quite out of the question. Renting would seem to be one of the few options and that means a very limited choice.

- **Live at home** with parents or some other member of the family; property may be adapted for use and maybe an extension has been built, but the big question is what happens when parents get older — or members of the family wish, or have to go their own way?
- **Live in a hostel** which will provide some care and meals with folks of a similar age group.
- **Buy one's own house** but this may not be possible.
- **Rent Accommodation** but this must be suitable and there is very little of it about.
- **Adapt Accommodation** but one must have the house to start with, rented or bought; some local authorities are better than others.
- **Live in a residential home** some of which are good, some of which are not, but living in them usually means some loss of individuality. However, you may get your own room. You will get three meals a day and your care needs met and their costs paid for, by local authorities and DHSS or both.
- **Live in a young disabled unit** which is usually attached to a hospital and using all the services available to others using the hospital.

Charles Moore.

- **Live in a hospital** because if all else fails, you may find yourself sadly living in one of the wards.

The greatest difficulty is, without doubt, that you may not want to be where you are but are there because other *people have made the choice for you because in reality there is NO CHOICE.*

Society could and should meet your needs and allow you the right to a 'Home of your own'. To get it you will need to 'Break Out' and here are the strengths you need or will need to develop: will power, a fighting spirit, patience, stickability, cheerfulness, self control, motivation, endurance, and to be realistic about yourself and your personal care needs.

Most important out of this list is 'will power' and 'motivation', most of the rest can be developed but 'will power' is a product of your inner self.

Advice for parents

Parents, too, have an important role to play. What I would like to say to them is contained mainly in one small phrase: 'Let your children go'.

Able-bodied children learn, and are subconsciously trained to go independent from birth. They are tuned to it, in almost every aspect of childhood and parents usually are deeply sad if their children have no desire to leave home and make their own way in life.

Should it be any less for disabled children? Yes, it will be harder and more difficult and parental support will be needed, but I suggest that the system and in some cases parents themselves are denying their children the opportunity to enjoy a 'home of their own' and an independent life.

The system of special schools, hospitals, residential homes and the funding of the care needs of disabled people leads to a low expectation of disabled children and parents must help to raise their sights and much more vigorously point their children to independence.

Please make the most of independence training use it when and wherever possible. Never miss an opportunity. Take up every course you can, and ask to see every assessment.

Don't make the big mistake of doing things for your child, not because he/she can't, but because for you to do it is more convenient *for you.*

Don't regard yourself as indispensable — age will catch up with you and what then, when you cannot cope anymore?

Don't stop your child from doing things without you — cooking, washing clothes, shopping, using money, etc., etc. There are risks of course — make them as few as you can but in the end you must let them take as many risks as you did.

Don't leave it until later.
Do work at independence training at home.
Do point forward, plan for it, work for your children's *own* home.
Do talk about it.
Do practise daily.
Do love them and do let them go.

If you are disabled you are not finished — not by a long, long way, and what I have said to parents means also a great deal to you. If you sit back and expect all things to come to you, you will be disappointed. It won't happen that way.

You have got to prepare yourself.

Find out what is available in your locality. Write to your Housing Department — insist on your needs for housing to be noted. If you don't get on the Housing Needs List you will not become part of Government Reports and therefore resources will not be given to your needs, because they will not be known — not *listed.*

Housing Associations can and do provide housing for special needs. Get your name on their waiting lists. Raise this issue with your local association/branch.

Whilst there is less money available today for housing and adaptations — due to financial cuts which are the result of Government policy — you still can get a home of your own.

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MEETING POINTS

SATURDAY WORKSHOPS

BANSTEAD Place Assessment Centre, in conjunction with East Surrey College, offers a range of Saturday training courses suitable for anyone responsible for the physical and emotional care, or the education of young people with special needs.

Banstead Place Assessment Centre.
Saturdays 10 am -4.30 pm.

PROGRAMME

Course A 1 March 1986 — Beyond Physical Caring: cost £10.
The emotional, social and relationship implications of the physical care of young people with severe physical dependence on others. Speaker: Gill Brierley — Dept. Head, Charlton Park School.

Course D 15 February 1986 — Using Drama Therapy techniques with young people with special needs: cost £10.
Speaker: Jan Potter, BA Dth — Dramatherapist.

Course E 15 March 1986 — Understanding and Practical Management of Epileptic Conditions: cost £10.
Speakers: Staff from ngfield Hospital School.

Course F 3 May 1986 — Helping Young People with Severe Head Injuries and their families to make emotional and physical adjustments to living: £10.
Speakers: Andrew Tyerman — Clinical Psychologist, Medical Rehabilitation Centre, Wolfson Centre, Atkinson Morley Hospital. Ruth Tyerman — Occupational Therapist, Banstead Place Assessment Centre. June Bendall — Ward Sister, Medical Rehabilitation Centre, Atkinson Morley Hospital.

Course G 7 June 1986 — Physical Intimacy among disabled young people: £15.
Speaker: David Lawler — Psychotherapist, Staff Trainer for Social and Health Service personnel.
Details: Ann Worrall, East Surrey College, Gatton Point, Redhill, Surrey, RH1 2JX. (Tel: Redhill 72611 ext. 252.)

LONDON LEISURE '86

A weekend of ideas, and workshops on leisure for disabled people. Saturday and Sunday, February 22 and 23. Westminster Cathedral Conference Centre, Morpeth Terrace, London SW1.

THIS non-residential weekend is for groups and individuals. It is to give them ideas on how to use their leisure. It will include speakers on sports, recreation and disability organisations.
Details: Ruth Cottrell, Spastics Society (London Region) 32/38 Osnaburgh St., London NW1 3ND. Tel: 01-387 5505.

COURSE ON DISABILITY AND SEXUALITY

Family Planning Association, 27-35 Mortimer Street, London W1N 7RJ. February 26.

THIS is an introductory course in personal relationships and sexuality for staff working with people with physical disabilities. The aim is to identify sexual needs of people who are disabled and how they might be met, and to develop the confidence and awareness of professionals. Course fee: £65.
Details: Family Planning Association (address above). Tel: 01-631 0555.

HOLIDAY SNAPS

Tadworth Court Children's Hospital, set in 22 acres of garden and woodland in Surrey, runs a summer HOLIDAY SCHEME for mentally and physically handicapped children aged 4-16. It also runs a fortnight for over 16s towards the end of the summer.

The cost of the holiday is £100 per week. The Hospital advises parents to contact their Social Services Departments in respect of funding.

Details: Sister Stepheni Fizio, Tadworth Court Trust, Tadworth Court Children's Hospital, Tadworth, Surrey, KT20 5RU. Tel: 073-73 57171.

Two specially designed self-contained COTTAGES are available at Irvine in Ayrshire. Each has an attic bedroom suitable for escorts, children, etc., whilst the ground floor is totally accessible and suitably equipped for the most disabled wheelchair users. Prices range from £55 to £95 per week.

Details: The Scottish Paraplegic Association, 3 Cargil Terrace, Edinburgh, EH5 3ND.

Home Farm is a summer HOLIDAY CAMP for 10-16 year olds. Although not specifically for disabled children, most activities can be enjoyed by both able-bodied and disabled alike. Activities include riding, archery, athletics, computing and swimming.

The toilets, however, are not accessible, so the child would have to be able to walk a few steps or come with a helper.

Details: Home Farm International Summer Camp, Home Farm House, Draughton, Northants NN6 9JO. Tel: 060-128 671.

Hindleap Warren Activity Centre at Forest Row in East Sussex is the location for Red Cross ACTIVENTURE HOLIDAYS. There are places for 160 handicapped young people on these holidays this year.

The activity weeks give the young people a chance to try everything from abseiling to environmental studies.

Details: Margaret R. Pope, Organiser — Activenture Holidays, British Red Cross Society, 42 Wilbury Villas, Hove, BN3 6GX. Tel: 0273 7375.

Travel information for the disabled in America is now available. A publication covers transport and accommodation and lists the main destinations and attractions. Special facilities for handicapped travellers are noted, and the book contains practical advice on medical care, money, electrical variations, use of telephones and a list of associations who could provide assistance.

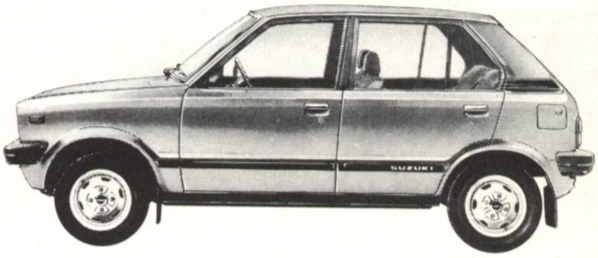
The United States Welcomes Handicapped Visitors is available from the US Travel and Tourism Office, 22 Sackville Street, London W1X 2EA. Tel: 01-4397433.

Rally is hard but rewarding

THE Beaujolais Rally, featured by famous cartoonist Gus on the cover of the last LINK, proved a hectic feat of motoring endurance for those who took part. Driving conditions were bad, with Arctic weather during the night, and tragically there were 15 bad crashes during the whole event.

ASBAH had the support of firms up and down t country who sponsored ca and took part in the 'Milea on the Clock' competiti which offered magnificent prizes for the guesses that were the nearest to the ASBAH car's mileage (460.6 miles).

Altogether ASBAH hopes to realise about £40,000 from the rally.



NATIONAL GARDEN FESTIVAL
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1st MAY – 26th OCTOBER 1986

£7½m Festival promises riches galore

ON the site where Josiah Wedgwood built his first pottery in the 18th century in Stoke-on-Trent, a massive reclamation is taking place to provide the centre for Britain's largest our National Garden Festival.

Graceful Etruria Hall, built in 1769 by Wedgwood still stands and is now the headquarters of the Garden Festival organisers. The derelict wasteland around it — once part of Shelton Steelworks — is being transformed at a cost of over £7½ million into a galaxy of gardens, woodlands and parkland.

It will contain an Arabian Nights type Festival Hall, a £1 million Greenhouse 2000, an 80 berth marina plus a host of showhouses, exhibitions and a Festival market place. The Festival will cover 164 acres and will be much larger than the one staged in Liverpool.

Education will play a part with nature trails, woodland walks and adventure playgrounds. There will be arts and crafts exhibitions and musical extravaganzas, street theatres, aerobatic displays and medieval jousting tournaments amongst a host of other events.

The architects of the Festival are paying particular attention to the needs of the disabled. The Festival organisers state:

"The main pedestrian routes will be spray and chip finish and therefore easy to walk on and also suitable for people using or pushing wheelchairs. A number of disabled routes around the site have been set up and where steps are part of the overall design, handrails or ramps will be included.

"Special toilet facilities will also be available at each of the toilet areas around the site. Car parking for the disabled will be close to the main entrances and dropped curbs and bench seating will be available for those waiting to be collected by car.

"Voluntary helpers and wheelchairs can also be booked in advance through the British Red Cross Society, who will co-ordinate the arrangements through their Stafford office (Tel 0785 58155). As well as the specially constructed pathways and access roads, disabled people can take advantage of the Festival train which loops its way around the entire site allowing the passengers to see every aspect of the site.

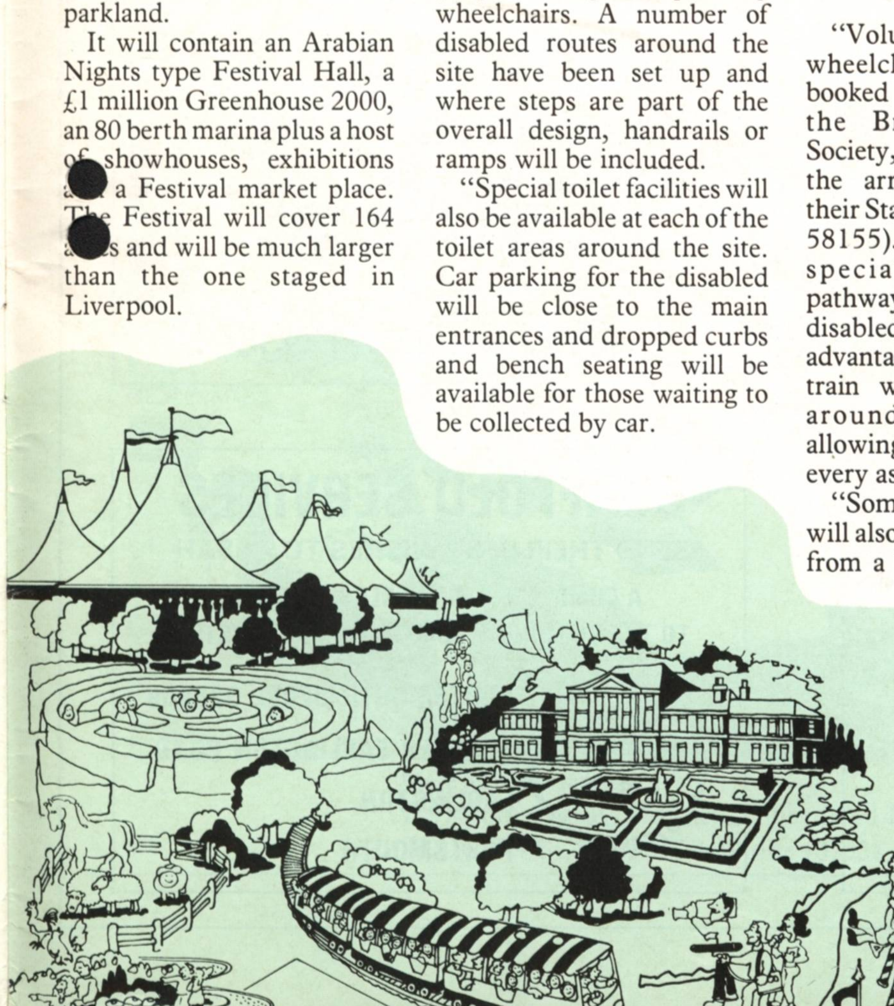
"Some disabled visitors will also be able to see the site from a breathtaking vantage point in the cable car system which stretches the length of the former steel works site from north to south."

Mrs Shirley Samworth has responsibility for the needs of the disabled at the Festival. To contact her or for more information about events and entry charges etc. contact the Organising office: 0782 289788.

Charges: adult day ticket — £4.50; children, senior citizens, students and the unemployed — £3; children under 5 — free.

There are discounts for season tickets, multi visits, group day and family day tickets.

A Festivaline Service is available. A recorded message gives details of the latest events and attractions. Tel: Stoke-on-Trent 274777.



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FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

Rate: £2.50 for 30 words max; £3.75 for 30-45 words; £5 for 45-60 words. Cheque or postal order payable to 'ASBAH'.

Adverts for next LINK (March/April) should be in by Feb. 10. Send to: The Editor, Mrs Sue Gearing, The Gables, Long Lane, Wrington, Avon, BS18 7NE. Tel: 0934 862279.

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

EXMOUTH, Devon. Fully equipped, self-catering 2 bedroom bungalow. Central heating. Approx 1 mile from town centre. Details: J. Harper, 70 Grove Road, Harpenden, Herts. Tel: (05827) 69213.

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.

PRIMROSE VALLEY. Fully adapted luxury caravan, sleeps 6. Shower, toilets, ramp. Many facilities on site. Details: Mr R. Vicary, 3 Wheatley Lane, Ben Rhydding, Ilkley, Yorks. Tel: Ilkley 607076.

ISLE OF WIGHT. Very well equipped chalet with easy wheelchair access. Sleeps 6. Indoor heated pool, club, shop. Details: Ring or write: Mrs S. Gully, Old Princelett, Apse Heath, Sandown, Isle-of-Wight. Tel: I.O.W. 863354.

SOUTH COAST. Very well equipped chalet with easy wheelchair access at Romney Sands Holiday Village. Sleeps 6. Many facilities including indoor heated swimming pools, large club house and entertainment provided. Very reasonable rates. Details: ring or write Mrs H. McLeod, 23 Harvest Ridge, Leybourne, Nr. Maidstone, Kent. Tel: West Malling (0732) 840868.

LOOE, Cornwall. Self-catering bungalow suitable for wheelchairs. Sleeps 4/7, well furnished and equipped. Colour TV. On holiday site with facilities. From £45 per week. Details: P. Cash, Farriers, School Road, Bransgore, Christchurch, Dorset. Tel: 0425 72055.

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Printed by K&SC (Printers) Ltd., High Brooms Industrial Estate, Tunbridge Wells, Kent.