Link

OCTOBER 1991 NO 136
Price 30 pence

The magazine for people with
Spina Bifida and/or Hydrocephalus

IN THIS ISSUE

MOTABILITY EXPLAINED

THE STATEMENTING MAZE UNRAVELLED

ASSOCIATION FOR SPINA BIFIDA AND
HYDROCEPHALUS
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CONTENTS

The magazine for people with spina bifida and/or hydrocephalus
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ACT NOW is a campaign by over 40 disability organisations to bring pressure to bear on the Government to implement the Disabled Persons Act 1986.

The Government argues that sections 1,2 and 3 of the Act, *which have already been passed by Parliament*, are unnecessary because the NHS and Community Care Act incorporate the principles of the 1986 Act.

ASBAH and other members of the ACT NOW campaign do not agree and are angry that the Government sees fit to ignore the will of Parliament in this matter.

Sections 1 and 2 of the 1986 Act give disabled people statutory rights to appoint an authorised representative to act on their behalf, in connection with the provision by local authorities of any social services. This statutory right is not present in the Community Care Act 1990. More importantly, under section 3 of the Disabled Persons Act 1986 local authorities have a specific duty to give a disabled person (or their authorised representative) an opportunity to make their needs known before the authority assesses the need for any services. Then, if asked, the authority would have to provide a written statement of what they decide the needs are and how they will provide services to meet them.

ASBAH believes these three sections of the 1986 Act to be fundamental to successful care in the community and essential to enable disabled people to gain independence, choice and control over their own lives.

The NHS and Community Care Act only provide codes of practice not absolute rights.

ASBAH is an active member of the ACT NOW campaign and is urging all local associations, and individual members to write to their MPs to ensure that this legislation is honoured.

LINK readers can also join the campaign by writing to their MPs to express their concern over the failure of the Government to implement in full the Disabled Persons Act 1986 and to ask for their MP's view on this matter.

COVER – Ruth Madoc receives a cheque from Deeping Lions President Stewart Jones and Clive Francis, Personnel Director, British Sugar. Details page 5.

Future fundrunners

The 1992 London Marathon may seem a long way off but for two men who haven't done any serious exercise since their schooldays it's definitely not too early to get into training. Kevin Daily (34) and Tony White (26) will be running for ASBAH in the Marathon in places provided from TSB's allocation. This is the second time TSB have said 'Yes' to Kevin - last year they helped him to publish his book, Jo's Story, about his seven-year-old daughter Joanne who has spina bifida and hydrocephalus.

Kevin says "the marathon training schedule is a killer, at the end of it we'll be running 61 miles a week!". LINK will be following their progress.

Anyone who would like to sponsor ASBAH's runners should call our Press Office on 0733 555988.

Jo puts Dad (left) and Tony under starter's orders

Folic Acid Latest

At a meeting on 12 September ASBAH's Medical Advisory Committee considered the recent folic acid trial which showed that supplements of this vitamin, starting before pregnancy, can prevent spina bifida.

GPs have already been advised by the government's chief medical officer to prescribe folic acid to women requesting it. But as it is being prescribed before pregnancy women have to pay the £3.40 prescription charge. Dr Martin Bax, chairman of ASBAH's Medical Advisory Committee is writing to the chief medical officer to ask that the prescription charge should be waived after the committee heard that a year's supply costs about £2.50.

At present, the only dosage available on prescription is 5mg and doubts continue to be expressed as to whether women need to ingest so much every day. After hearing that the MRC reported no undue side-effects from a daily 4mg dose, the ASBAH committee considered that no harm would come from taking 5mg a day. The committee will review the dosage in the future in the light of experience.

ASBAH still emphasises the importance of a balanced daily diet in the prevention of spina bifida - including plenty of lightly-cooked green vegetables, nuts, fruit and folic acid-enriched bread. But advice given by some of the media to eat more liver should not be heeded - liver also contains large amounts of vitamin A which could prove detrimental to the foetus.

Star Support

Ruth Madoc, pictured left and on our cover, was the special guest at a recent charity show in Peterborough which raised £2,000 for ASBAH's Fund a Fieldworker Campaign. The Hi-de-Hi star agreed to lend her support to our campaign in Cambridgeshire after visiting ASBAH House.

The show was organised by a local men's community service club - The Deeping Lions Club - and involved local scouts, music and dramatic societies. The evening was sponsored by British Sugar and all proceeds from ticket sales at the packed theatre went to Fund a Fieldworker.

ASBAH's business liaison manager Paul Wootton said, "We were delighted with the way the evening turned out and with this tremendous boost to our Campaign."

Miss Madoc joined in the finale song - There's no business like show business - after accepting the cheque on stage.

A Winning Bet

ASBAH also benefited from another show in the same week when we received a cheque for almost £2,500 from the TV game show YOU BET.

DJ Bruno Brookes, appearing on the show, nominated ASBAH as his charity and, luckily for us, he won. The show had other ASBAH connections - it's hosted by Mathew Kelly who visited the first Mobility Week in 1989 and Ruth Madoc was also a celebrity on the panel.

DRUG WITHDRAWN

Micturin (Terodiline) has been withdrawn from use, if you are taking this drug please contact your G.P.

Glyn Roberts Memorial Trophy

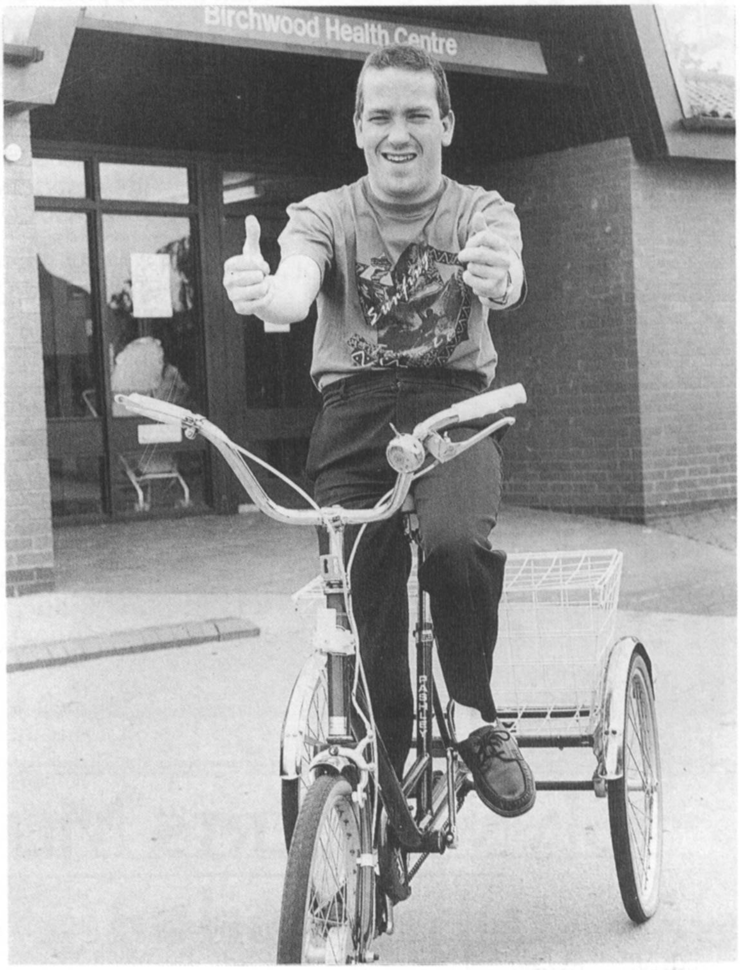
GLYN ROBERTS was a highly valued member of the ASBAH telesales team who died last year from a heart attack - he was just 45 years old. Tom Logan, Telesales Manager said "Glyn has been greatly missed he was my number two and a real financial asset to ASBAH".

So when residents of Glyn's home village of Eagle, near Lincoln, challenged Glyn's ASBAH colleagues to a cricket match in his memory they were delighted to accept. And on 1 September ASBAH played Eagle cricket team in the first 'Roberts Memorial Trophy'. The event also included a rounders match and raffle, raising over £300 for ASBAH as the spectators sponsored batsmen and bowlers and all players paid £1 to enter the games.

The winners' shield was presented by Mrs Jean Roberts to Eagle cricket team, who won the match. Next year ASBAH will attempt to win back the trophy when they play on their 'home ground' at Peterborough. After their exertions the two teams enjoyed a barbecue and disco at the village pub which had been organised by Eagles captain, Neil Richardson.

The teams gather before the match , Mrs Roberts holds the shield while Appeals Manager Roy Johnston (in the hat!) shakes hands with Neil Richardson.

JOURNEYS END



STEVE Robinson and Tony White both returned safely from trips they took this summer - but the similarity ends there.

Steve, a member of Lincoln ASBAH, completed over 18 miles on his three-wheeler to raise money for equipment for his local health centre. It was a thank you from Steve for the medical treatment and help he has received from Birchwood Health Centre over the years - he has spina bifida. The marathon took Steve two hours and 56 minutes.

MEANWHILE Tony White from Peckham was busy canoeing his way down the Rhine, on an adventure trek which totalled 700 miles. It wasn't all plain sailing - it's not much fun shooting the rapids when you're suffering from a 'holiday tummy' or having your inflatable canoe 'burst' when it hits some broken glass in the shallows. But it was all worth it when Tony achieved what he set out to do and broke the record as the only disabled canoeist to make the trip.

He's now returned to normal life but there won't be many dull moments for Tony, who has just had his 16th birthday, is about to start driving lessons and is busy studying for his GCSEs.

Marriage Lines

Karen Grant's parents were very active members of the Somerset Association when it was formed 16 years ago, then of course Karen was just a little girl - but look at her now! This summer Karen got married to Martin Dale at St Mary's Church, Taunton, followed by a honeymoon in Cornwall.

The couple met at Harcon House - a hostel where Karen was living and where Martin had come to recover from a serious road accident. Four years later they are both working and have a flat in Taunton. We wish them happiness for the future.

EXCHANGE & MART

Free Advertising

EXCHANGE & MART are offering free private classified advertising in their sections for Disabled Needs & Mobility and Adapted Cars. So if you have anything for sale, or wanted, from bathroom equipment to a wheelchair you can place an ad by phoning 081 6806800.

This weekly magazine will also be including a new feature for disabled readers - an Information Box with details of places to visit, sports, activities and advice lines. You can have your club, event etc mentioned in this section, for free. Enquiries to Hilary Jay 0202 671171 ext 130.

Statements in Time

THIS time last year IPSEA (Independent Panel for Special Education Advice) alerted parents to the need to get draft statements completed by the beginning of May 1991. This advice followed a large number of enquiries to IPSEA from parents who had received their statements late in the summer term and so felt they had no choice but to accept them without question - otherwise their child might be without a school to attend in the autumn term.

It's advice worth repeating - so draft statements for children starting school in September 1992 should be completed by the beginning of May 1992.

For more information see Peter Walker's article on statementing in this issue.

Hazard Warnings

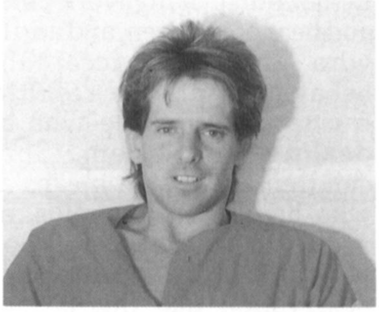
TWO HAZARD notices have been issued by the Scottish Health Service. The first concerns the "Smiley Walker" supplied by Joncare Ltd (who are in liquidation). When using the Smiley Walker a child stumbled and trapped its head between the two push handles. The SHS says this product should be withdrawn from use until further notice, the possibility of modification of the walker is being investigated. Enquiries about this item should be made to Scottish Health Service, CSA Supplies Division, Trinity Park House, Edinburgh EH5 3SH, telephone 031 552 6255 ext 2594.

The second warning is regarding the "Snugseat Buggy" manufactured by Gimson Tendercare Ltd. There have been a number of incidents where the wheels fitted to the latest model of the Gimson Snugseat Chassis have become detached in use. Incidents of failure of the brake mechanism have also been reported. All Snugseat buggies should be withdrawn from use immediately states the SHS.

Further enquiries on this product should be addressed to Mr Jonathan Adams, Gimson Tendercare Ltd, 62 Boston Road, Beaumont Leys, Leicester LE4 1EZ, telephone 0533 366779.

A picture of winter

In the February issue of LINK we asked readers to enter the Sunrise Medical Calendar competition to illustrate the months of January and February for their 1992 calendar.



The judging is now complete and we are able to show you the chosen illustration - a painting by Frank Rook.

Mr Rook *pictured right* lives in Barnsley in Yorkshire and has been painting since he was 16, though he's only been doing so seriously for a few years, he is now 36 and this is the first competition he's entered. The demise of his own business, due to the recession, making fabric dolls and children's clothes, has left Mr Rook with even more time to paint. All his paintings are from "life" and he favours landscapes - "I just get in my car and go".

The competition to find six illustrations for the complete calendar invited entries from six national charities. The illustration for May/June was submitted by Amanda Knapp, a member of the spinal injuries group, whose photographs we used to announce the competition, Ms Knapp was also a prizewinner - her entry being chosen as third overall. The youngest entrant in the competition was another ASBAH member - eight year old Christina Morgan from St Austell in Cornwall.

Judges for the competition were drawn from the National Disability Arts Forum, the International Guild of Artists, the Disabled Photographers' Society, and Disabled Magazine, with Julian Cobbledick, Marketing Director of Sunrise Medical. Mr Cobbledick said,"We have been delighted with the response to this project. We wanted to produce something that was not only a showcase for the many creative talents of disabled people but also a useful product for people to refer to...we've done just that."

Frank's winter scene held by two of the judges - Tom Samson and Lynne Lister.

The calendar is due to be printed around mid October. If you would like a free copy, send your name and address, with an 88p stamp to cover postage, to: Special Edition Calendar 1992, Sunrise Medical Ltd, Fens Pool Avenue, Brierley Hill, West Mids DY5 1QA.

Behaviour Problems

Leonie Holgate investigates and offers some solutions

Some children with hydrocephalus can exhibit behaviour problems - disabled living adviser Leonie Holgate identifies the problems and offers practical advice.

A child who is spitting, swearing, kicking and throwing objects is not a pretty sight. The parent who is trying to deal with it feels acutely embarrassed and those who witness it are relieved that the child is not their problem. Often there are a few "tuts" and "if that were my child" comments. It is so easy to have the answers when one is a spectator and so easy to draw the wrong conclusions.

In the course of my work I meet and hear of children, and adults, who have unacceptable behaviour and the resulting frustrations of those who are dealing with them. Some children, but by no means all, who have hydrocephalus, are prone to outbursts of poor behaviour. It appears from observation that this is more likely to occur in cases of hydrocephalus alone. Children who have spina bifida and hydrocephalus are usually much more passive and compliant.

There is no reason to expect that because a child has hydrocephalus, they will develop behaviour problems but for those who do exhibit this problem, it causes great stress for the whole family and for this reason needs to be recognised.

Not a great deal of work has, apparently, been done in this field and there is very little written about unacceptable behaviour and hydrocephalus. There has been considerable work on learning difficulties and types of behaviour relating to that eg short concentration span, poor memory etc. but temper tantrums and aggression have, perhaps, been seen to be the result of poor or inappropriate handling by the parents. In fact, it has probably not actually been seen by the doctor or consultant at all because the child is quiet and well behaved in the consulting room, overawed by the surroundings. Here is a dear little, sociable child; how can they say and do all the things that the parents are reporting? It is very natural to draw the conclusion that the parent is at fault. I am convinced that this is the wrong assumption to make.

Several parents have said that there are periods of a week or weeks, when their child is a happy and delightful little person but then they will start to have outbursts of temper and in some instances develop obsessive behaviour. This is very difficult for the family to understand and to live with. Some families are fortunate as they have access to a clinical/behavioural psychologist who can suggest behaviour modification techniques and these appear to help, up to a point, but they may only be papering over the cracks if the underlying cause has not been identified.

One approach, which can help to identify where the problem lies, is to keep a diary of when and where the bad behaviour occurs and what nature it takes. After a period of time a pattern may begin to emerge which can be useful in spotlighting the trigger factors.

Trigger factors may be -

- sudden change of routine
- unexpected noises
- unstructured situations eg school dinners
- hunger, low blood sugar levels
- variations in the ventricular pressure eg after a night's sleep or after being up all day
- tiredness, being below par.

This is not a definitive list and should be used with caution. These trigger factors are mainly hypotheses but as more and more cases are seen, certain observations begin to be repeated. No two cases are quite the same but there are some general characteristics. Of one thing I am certain - the parents' observations should be listened to seriously. I have learnt a great deal from careful reports kept by the mother and from teachers. These behaviour problems are not, in the majority of cases, stemming from poor handling but are as a result of the damage sustained by the effects of the hydrocephalus, be it unidentified learning and perceptual problems, damage to the inhibitory centres of the brain or fluctuating intercranial pressure etc.

What are the problems?

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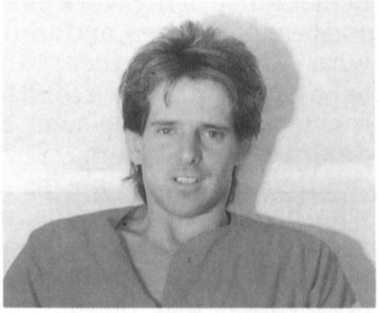

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difficulties are spitting, biting (both themselves and others) hitting, refusing to eat, throwing objects about, and head banging. At the end of an outburst like this the child may be quite exhausted, perspiring and burst into tears, or collapse into sleep. Occasionally the child hits out at a brother or sister in a compulsive way, almost routinely, as though they cannot prevent the action. Recently, speaking to a mother about this problem, she reported that once her child had started to do something unpleasant it appeared that he had to complete the course of action and was unable to change direction even when he knew punishment awaited him which he did not like.

Many children are very obsessive of the mother's attention and come between her and anyone she may be talking to, destroying social contacts. In school the child may make demands on the teacher's attention, interfering with her control of the class.

Some children develop an obsession for certain items. Two examples I have come across are buttons, and wheels or circular motion. The child had to press any button he saw which could have disastrous consequences for the microwave! The other child loved to watch the washing going round and round in the washing machine and was obsessed with the wheels on cars and buses. This manifests itself as more than a passing interest.

There are similarities with agrophobia or autism in some of the children but they do not quite fall into either category. The reasons behind the problem will be different. One young man loathed to go out, preferring to stay indoors or in the garden, and required a great deal of encouragement to visit anywhere outside the home. Much of this, I think, stemmed from difficulty with gross spatial awareness and, therefore, a dislike of the unknown. Some children do not appear to have a strong bond with their parents and treat everyone as their friend - whoever they see they know. This can be quite disturbing for the parents as they can feel rejected, although the child does not intend this.

These idiosyncrasies are often seen in conjunction with the more aggressive behaviour. The impression is that once the brain has been programmed to follow a certain pattern, rather like a computer, it has to go that way.

Are there any solutions?

There are certainly no simple sure-fire answers but there are a variety of steps which can be taken to ease the situation.

If the child's behaviour is deteriorating then make an appointment to see the consultant and take a note of all relevant observations. It could be that there is a fault with the shunting system and this requires attention.

The advice of a clinical/behavioural psychologist may be sought and it is recommended that he/she contacts ASBAH to ensure that they can apply their knowledge in the light of the hydrocephalus.

Parents and school need to work together so that the handling of the child is consistent. If a behaviour modification programme is to be successful it must be consistently applied.

Avoid discussing the child's behaviour in front of him as this only serves to reinforce bad patterns and he becomes aware that it draws attention.

Each child will require a specific programme to suit the situation but generally a positive approach, rather than a negative one, will be more effective. Examples of this would be: if the child were about to pull the cat's tail, avoid saying "don't do that" but "put your hand down, now stroke the cat gently" or, in a slightly different situation, when the child resists going to school, avoid saying "stop dragging" but try "let's look for an aeroplane". This constitutes a mixture of positive direction and diversionary tactics.

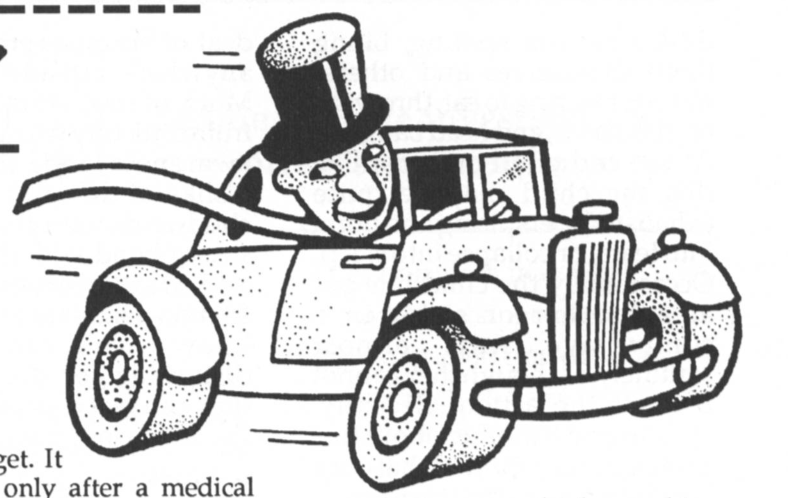
Use the child's abilities through speech (ideally his own recorded voice) and music, which are usually areas in which they are confident and may well excel, to introduce good behavioural concepts.

Whenever there has been success and the child has controlled his behaviour, give praise and talk about how well he has done to enable him to be aware that he is master of his feelings and actions.

Readers letters on this topic would be welcome and could help stimulate further ideas. The author would also be pleased to have comments and experiences from families.

MOTABILITY

If you 'don't know' what Motability is, who it's for and how it can help you get the car you need, here's some help from the man who 'does', John Naudé (disabled living adviser on mobility) explains the scheme.



MOTABILITY is a charitable organisation which was created by the Government in 1977 with the help of five major banks, National Westminster, Midland, Barclays, Lloyds and the Royal Bank of Scotland. Motability is aimed at helping people in receipt of Mobility Allowance to obtain good value for money when buying or hiring a car or electric wheelchair. Its leasehold fleet is the largest in Europe and in 1988 the organisation received a Royal Charter.

GETTING MOBILITY ALLOWANCE

Mobility Allowance (MA) is a weekly benefit of £29.10 paid to people who are unable or who are virtually unable to walk, or for whom walking would lead to a serious deterioration in their state of health. When you apply you must be over five-years-old and under 66 – though it can be retained after this age. If you think you may qualify, you can apply on form N1211 available from DSS offices. Fill in the claim form attached to it and send it to the Mobility Allowance unit at the address printed on it.

If you are changing from an invalid car or trike you will need leaflet N1225. If you do not get any acknowledgement within three weeks write a follow-up letter to the unit asking if they have received your claim. If necessary you can deliver your claim form or letter to your nearest DSS office with a note asking them to forward it to the Mobility Allowance Unit.

It is strongly advised that you get help from a local advice centre, or your fieldworker or ASBAH when applying. People who do get advice stand a better chance of success.

MA is notoriously difficult to get. It is awarded only after a medical assessment and unless your case is very clear you may well be turned down and have to appeal, but do not despair as many appeals are successful and we at ASBAH will be happy to assist in any such appeal.

Once a person has Mobility Allowance a car can be leased or purchased through the Motability scheme. ***In the case of a child who has been awarded Mobility Allowance the parents can lease or purchase a car, using the child's MA, through the Motability scheme.***

HOW DOES MOTABILITY WORK

Motability runs hire purchase and contract hire (lease) schemes which are broadly financed by payments from disabled car owners (mostly in the form of Mobility Allowance). These schemes are backed by several hundred million pounds provided by the major banks and administered by the MFL (Motability Finance Limited), a company set up by the five banks mentioned above. Motability also has a charitable unit which can help with the expenses which the motorist cannot meet eg the cost of adaptations.

The Motability scheme works through an individual's MA being paid directly to Motability Finance Limited by the DSS. The organisation then uses it to pay for a motor vehicle or an electric wheelchair on either a hire purchase or hire contract (three year lease) basis. If you have a lease Motability also pay for servicing, repairs and some of the cost of insurance. If you pay for your vehicle on hire purchase, you can keep some of your MA back to finance running costs and insurance.

THE COST TO YOU

Although it might sound as if Motability vehicles are obtained virtually free of charge, the reality is that for most larger cars you have to find a deposit of up to £5,000 on the lease scheme and between £70 - £10,000 on the hire purchase scheme (more for special vehicles like the Chairman). In addition, many people have to fork out several thousand pounds for adaptations. Some disabled drivers, particularly those who are severely disabled need to have a lot of work done to their car by way of special controls, hoists or door adaptations before they can use it. Such work is very expensive to carry out and makes it very difficult for some people to afford.

However, Motability may also be able to help with the costs of adaptations and sometimes deposits, particularly if you are renewing the lease with them. The organisation has always run a grant scheme but this used to be very restricted. In the past three years the establishment of two new funds means that many more people are being helped. Motability now states that it only fails to meet customers' requirements on three or four cases each month.

In 1988, on celebrating its tenth anniversary, Motability received £10,000,000 grant, funded by the Government and some of the major banks, and set up a trust fund. The money was invested and the interest is now being spent to help people who need to fund adaptations and a deposit when they change to a new car at the end of a three year lease.

The fact remains that some disabled people are still unable to obtain a vehicle because they cannot afford one. Some have problems with the means testing of the Motability Grant Scheme or are put off by it. Some do not know about the fund and others believe that adaptations which Motability will finance are not sufficient to make them independently mobile.

The DSS announced recently that they will donate an extra £1,000,000 per annum for the next three years to Motability in the shape of the Mobility Equipment Fund. This money has again been given to help people with the extra costs of adaptations. For the first time grants will be available to people who have not obtained the vehicle through Motability, but the fund is not being widely publicised so only time will tell how the money is used.

WHICH MOTABILITY SCHEME

- You can lease a car if you have been awarded a Mobility Allowance to run for more than three years

- You can buy a new car on hire purchase if you have been awarded a Mobility Allowance which will run for more than four years

- you can buy a used car if you have a Mobility Allowance for two years plus the time it takes for your application to be processed and the vehicle delivered.

Contract Hire (Leasing)

Most people who use Motability lease their cars. At present each lease agreement runs for three years although there are plans to introduce a five year scheme. Motability supplies the hire price list which contains over 200 approved vehicles and only these models can be leased through the scheme.

When you take up a leasing agreement you surrender your MA to Motability and you usually have to make an initial payment. Though, as mentioned above, all maintenance and servicing costs are covered through the agreement, plus AA breakdown service and a low cost insurance policy (people with existing leasing agreements will continue to pay separately for insurance until their current lease expires). After three years you have to return the car and apply for a new one (which means you may have to find another initial payment). It could be difficult to change your car during the period of lease.

There is an excess mileage charge which starts at 12,000 a year. The cost per mile between 12,000 and 15,000 miles is 5p plus VAT, at 15,000 to 20,000 miles the cost is 8p plus VAT and over 20,000 miles the cost is 10p plus VAT.

The insurance cover under the lease scheme is a block policy so you cannot qualify for a no claims bonus. Young and inexperienced drivers may be expected to make a contribution towards the cost of a claim.

Hire Purchase

On the hire purchase scheme you are buying the car and can hang on to it for as long as you like. Generally, people who need extensive adaptations use the hire purchase as they want to keep the car for more than three years. You can also buy a used car on hire purchase. If new, the vehicle can be paid for over a period of four, four and a half, or five years. If you buy a used car, payments are made over either two or three year periods. A deposit is required in both cases which can range from under £1,000 to several thousands. Insurance, servicing and motoring association membership are **not** included in this scheme. Adaptations must be paid for. At the moment you still have to pay car tax on vehicles purchased through the hire purchase scheme but it is hoped that this will change in the future.

Used vehicles are subject to an AA inspection, the result of which is sent to Motability but you will have to pay for the cost of inspection.

INITIAL PAYMENTS

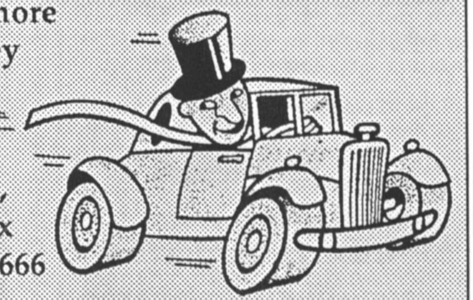
Many people need large or heavily adapted cars and have to find several thousand pounds to pay for the deposit or alterations. If you have not got this money you have a number of options.

- You can ask a local charity to help.

- You could consider whether cheaper adaptations would be possible (eg do you need a turning seat to get in or would a transfer board do). A driving assessment centre such as Banstead may be able to help you decide.

- You can apply to Motability's own charitable fund which may help towards the cost of adaptations or initial deposit on leasing a vehicle.

If you want to know more contact Motability. They have booklets which cover all the schemes at:



Motability, Gate House,
Westgate, Harlow, Essex
CM20 1HR Tel: 0279 63666

Do not forget many car manufacturers have cars which are particularly suitable for disabled drivers eg the Disabled Driver Ford Escort. But if you feel you need further information or advice on Motability or which car may be the most suitable to your specific needs, then please do not hesitate to contact me.

CURRENT RESEARCH PROJECTS

ASBAH supports a range of vital research projects and here we give brief descriptions of those currently in progress.

"Genetic Linkage in Families with X-linked Spina Bifida and Related Neural Tube Defects."

Dr Gudrun Moore, The University of London, Institute of Obstetrics and Gynaecology.

Dr Moore is studying a large Icelandic family showing an x-linked inherited form of spina bifida. The purpose of this research is to pinpoint the chromosome to study and to map its development. As spina bifida is a multifactoral disability, the researchers hope that their work will help isolate the various genetic/ inherited factors. The cost to the Association is £33,000, and the project is due to be completed in December 1991.

"Bacterial Colonisation of CSF Shunts and its Amenability to Non-Surgical Treatment."

Dr Roger Bayston, University of London, Institute of Child Health.

Research to prevent colonisation of shunts without surgery remains a top priority of the Association. It is hoped that this project, which will cost £51,000 and last until 1993, will lead to successful and more systematic non-surgical treatment of shunt infections.

"Immunological Studies in Patients with Cerebrospinal Fluid Shunt Infections."

Dr Roger Bayston, University of London, Institute of Child Health.

Since shunts were first used to control hydrocephalus, a major cause of failure has been infection of the shunt. Diagnostic serological tests were introduced by this group in 1972 and this project will be looking for better ways to diagnose infection, leading to earlier treatment.
ASBAH funding is for three years from July 1989 at a cost of £51,500.

"A Study of Adolescents with Spina Bifida and Hydrocephalus."

Dr Martin Bax, The Westminster Children's Hospital, London, Department of Child Health.

Many people with spina bifida and hydrocephalus seem to have very poor self-image and, as a result, very little social contact. Dr Bax and his team have studied many of the effects of disability on young adults. A recent study, also partly funded by ASBAH and featured in the February 1991 issue of Link, studied health and social needs and uncovered huge gaps in provision. This study, which is entirely funded by ASBAH, is highlighting enormous difficulties and identifying areas where ASBAH must expand services to young people. The cost of this project is £65,000.

Some of the areas where particular difficulties have been identified are personal and sexual relationships. Our Research Fellow, Madeleine Blackburn, is working with Dr Bax but current financial problems mean that some of their work may be seriously curtailed. The project needs another £31,707 to enable it to continue for the next two years.

"The Development of Body

Image and Self Concept in Children and Young People with Spina Bifida."

Mr Peter Appleton, Chief Clinical Psychologist, Wrexham Maelor Hospital, Clywd.

During development, the young person with spina bifida may experience challenges and obstacles to his or her growing autonomy, including mobility difficulties, continence problems, problems of body development and function, specific cognitive and educational difficulties, emotional problems and a lack of knowledge about disability and its implications.

The development of social integration is also potentially impaired, particularly if there is family stress or reduced opportunities for normal social mixing.

This research aims to portray the exact nature of psychological need in young people with spina bifida. Data analysis, in collaboration with Bangor University, will lead to recommendations concerning assessment and intervention methods for psychological aspects of physical disability in youth.

This is a two-year study, due to end in December 1991, and the cost to ASBAH is £48,000.

"Folic Acid Metabolism Associated with Neural Tube Defect"

Professor M Levene, University of Leeds, Department of Paediatrics and Child-Health.

The aims of the projects are to characterise the mechanisms by which vitamin supplementation in early pregnancy reduces the recurrence of birth defects of the brain and spinal cord to search for a marker in maternal blood that would open the way to identifying women at risk of NTD births.

The first year of this study is now complete and a further grant of £12,469 has just been made to extend the project. The study is now due for completion in December 1991.

"An Alternative to Bowel for Bladder Reconstructive Surgery in Children with Neuropathic Bladders."

Mr Padraig Malone, Southampton General Hospital, Wessex Centre for Paediatric Surgery.

This is another area of particular importance to individual people with spina bifida. In the first instance, Mr Malone will be doing a feasibility study which will only cost in the region of £3,000-£4,000. If, however, this proves to be successful, we shall be looking for £60,000 over two years.

"Open Spina Bifida: The Survivors reviewed in their Third Decade."

Dr Gillian Hunt, Addenbrooke's Hospital, Cambridge.

This project will, we are sure, give us valuable additional information about this group of young people. The cost to ASBAH is £1,500 over one year. The reason that the costs are so low is due entirely to the fact that Dr Hunt is most generously giving us her time. We are most indebted to her for this.

"Risk of Neural Tube Defects in the Babies of Women who Conceive after Treatment for Infertility."

Dr Michael Murphy, University of Oxford, Department of Public Health and Primary Care.

This study which started in July 1990, was originally for a period of one year for the sum of £10,000. The sample of babies with neural tube defects identified was much larger than originally anticipated and an additional grant of £5,000 is therefore being considered so that full use can be made of the information available from this larger cohort.

Obituary

It is with great regret that we announce the death of Carolyn Smith, former fieldworker for NW London.

Carolyn was a vivacious and popular member of the ASBAH staff who resigned in May this year when she moved to Bradford to marry Richard.

She first joined ASBAH as accommodation officer in June 1986, leaving in July 1989 to go back to college to further her housing qualifications. Carolyn later decided that the course was not really what she wanted and we were very pleased when she accepted the post of North London Fieldworker in October last year. She quickly became a valuable member of the team.

Carolyn died suddenly at the end of September, she was 28.

She will be sadly missed and we send our deepest sympathy to her husband Richard and her family.

Teresa Cole, fieldwork manager.

On the right track

A visitor to the West Somerset Railway using the newly fitted lift

When staff at the West Somerset Railway, the longest preserved steam railway in Britain, decided to improve facilities for disabled travellers they didn't do it by halves. After hard work both fundraising and renovating they now have a whole carriage kitted out for those with mobility difficulties. The Lorna Doone Special Visitors' Coach has tracking for 10 wheelchairs, deep picture windows to provide a good view of the Quantocks and Somerset countryside, through which the train journeys, and a spacious accessible toilet. Access to the carriage is provided by a pair of Ratcliff tail lifts - the first to be fitted to a train in this country.

At the official launch of the Lorna Doone, Sir Peter Baldwin, Chairman of the Disabled Persons Transport Advisory Committee said "This excellent initiative by the West Somerset Railway amply demonstrates what can be achieved to open up new horizons for disabled travellers. Not only the individual wheelchair user, but whole families and groups."

Car Control

A report issued by the Department of Transport and the TRRL (Transport and Road Research Laboratory) suggests that improvements could be made to controls for disabled drivers. In particular they found that excessive effort was needed on some cars to operate hand controls and steer the vehicle.

Drivers' comments included in the report criticised the accelerator/brake controls which are normally located behind the steering wheel as these require the driver to use his fingers to operate the controls while his thumb is hooked over the steering wheel. Drivers also complained about the shape of controls - making them uncomfortable to use - such as the handbrake control and steering knob. The report says these controls should be better designed to match the part of the body with which they have contact.

The report "Strength Abilities of Disabled Drivers and Control Characteristics of Cars" by Paul Kember, can be purchased from the TRRL, Old Wokingham Road, Crowthorne, Berkshire RG11 6AU. It costs £14.00, cheques should be made payable to TRRL.

Mobility Discounts

Discounts available to disabled customers from motor manufacturers, cheaper tyres, exhausts and batteries, discounts on ferry crossings and concessions on bridge and tunnel tolls are listed in a new leaflet from the Mobility Information Service. To obtain this free leaflet send a stamped addressed envelope to 'Discounts and Concessions', National Mobility Centre, Unit 2a Atcham Estate, Shrewsbury SY4

Holidays for All

The Holiday Care Service, supported by Barclays Bank, has produced a series of free leaflets giving details of accessible holiday accommodation in each of the Regional Tourist Board areas and also for Wales and Scotland. Every hotel in the guides has been inspected. The leaflets should be freely available from tourist information centres throughout the country, or you can get them direct from the Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW.

ORANGE BADGE CHANGES

Most of the changes proposed for the Orange Badge Scheme are to be implemented this autumn. The changes include:

*redesigning the orange badge as a personal passport-type document with space for a photograph of the holder

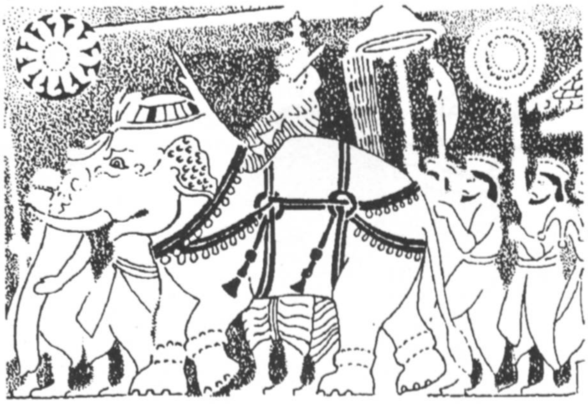
*increasing the time limit on yellow line waiting from two to three hours

*giving recipients of Mobility Allowance automatic entitlement to badges.

*more guidance to help GPs and issuing authorities in administering the scheme

*continuing consultation with local authority associations to make sure that only those who are entitled to receive Orange Badges actually get them.

Journey of a lifetime



Fancy travelling the silk road from Pakistan to Peking, or trekking through Zimbabwe and Zambia? Both trips may sound like impossible dreams but they are dreams which will come true for 36 disabled and disadvantaged youngsters who are chosen to join these trips in July next year. The journeys are organised by JoLt (Journey of a Lifetime trust) and each person is asked to raise £500 towards the cost of his/her trip - the major part though is paid by the trust - another £2,500.

To apply you can either be nominated by an adult or nominate yourself - provided there are two adults willing to support your application.

Further details are available from The JoLt Trust, c/o Mrs Dorothy Dalton, High Brow, Harrow park, Harrow on the Hill, Middx HA1 3JE, telephone 081 869 1214. Hurry, completed applications must be in before the end of the year.

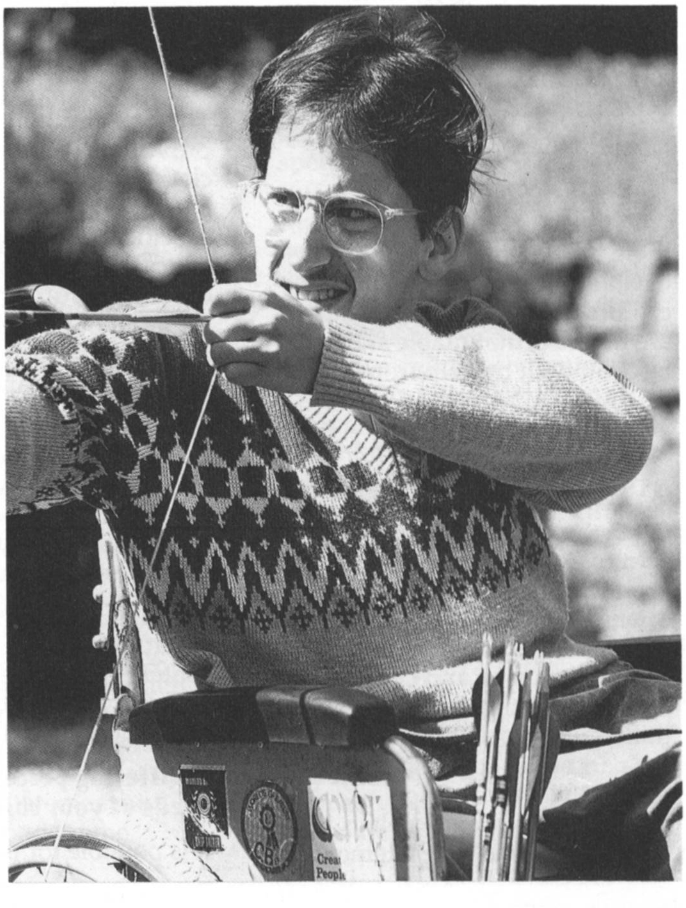
A chance for adventure

TEN of the country's holiday activity centres have got together to produce a leaflet showing what they have to offer for young people with special needs, on their own or with family or friends.

They feel that more young people could be benefiting from the opportunities available at these centres, not only helping personal development and confidence but having a really enjoyable time. The problem is that most people try to book during the months of July and August so these times are booked solid a year in advance but you could go at other times, even in winter. Many schools are happy to allow 'time off' for this purpose because of the benefits to the individual.

Centres mentioned in the leaflet include Stackpole in Wales (which has been featured in LIFT in the past). There are also centres in Norfolk, Yorkshire, Scotland, Cornwall and Cumbria - this one was given an enthusiastic report on TV's Travel Show in September. The types of activities provided by the different venues include riding, pony driving, abseiling, archery, orienteering, sailing, camping, canoeing, to nature study and arts and crafts.

To obtain a copy of the leaflet "Adventure for All" contact BSAD tel. 071 383 7277.



Archery is one of the many sports offered at Adventure Centres

Finding your way through the Statementing maze

Following his article in the last issue on the need for a Statement, Peter Walker discusses the hurdles parents may encounter in the process and suggests ways to overcome them.

STATEMENTING is necessary for any child who is perceived to have or could have a special education need. Children with spina bifida and/or hydrocephalus are most certainly in need of careful assessment to make sure that their medical, social and educational needs are adequately dealt with whilst at school. But many parents are reticent when it comes to starting the Statementing process, either because no particular problems are immediately obvious, or they have heard of the difficult experiences of other parents. And headteachers and educational psychologists may not see the necessity of Statementing a child with hydrocephalus because there are no physical signs of disability. Certainly the process can produce problems but these are not insurmountable and can be dealt with by help from ASBAH.

Difficulties you may face

Δ Delay in getting a Statement

Often the time taken from the start of assessments to the production of a final Statement can be up to two years. Meetings and paperwork along the way can be confusing and cause delays. Sometimes one feels that this could be delaying tactics on the part of the Local Education Authority! One distinct disadvantage of such delays is that, by the time the Statement is completed, the special educational needs of the child could have changed.

Δ Vague definitions of your child's needs

Sometimes Statements of Need are very vague and use words or phrases which could be interpreted in a variety of ways by different people. Comments such as 'physiotherapy as appropriate', 'individual attention required in small groups' and 'requires special educational programmes' are not specific enough.

The type, content and amount of provisions necessary should be clearly spelt out. Section I of the Statement, which deals specifically with special educational needs, should describe in full what the needs are and not be merely a diagnosis, such as, "X has hydrocephalus and a shunt leading to the peritoneum"

In Section III, which deals with Special Educational Provision, provisions must be made specific for each and every one of the special needs mentioned.

It is vital for parents, on receipt of a draft Statement, to examine its contents very carefully. If necessary, consult ASBAH for discussion and advice.

Δ Differing perceptions of the needs of your child

It is possible for parents and professionals to have different views on the special needs of children and this can produce conflict. It is very important that there should be dialogue and consensus of thought rather than confrontation when the Statement is being compiled.

Often the parents, having spent much time in caring for their offspring, know considerably more than anyone else about their child's medical, psychological, emotional, social and physical problems. Because of this it is vitally important that, during the assessment process, parents send the Local Education Authority a profile outlining details of the child's early years, the present situation and some general personal views on how the child's needs can be best provided for. Help with the preparation of this document can also be given by advisers at ASBAH.

Δ The Statement has been made to match the resources available and not the needs of your child

It is regrettable that, on occasions, LEAs formulate Statements according to the present resources available, and not according to the individual needs of pupils. Understandably, financial constraints place great burdens on Authorities, nevertheless it must be remembered that the meeting of the special needs of a particular child is of paramount importance. Parents are encouraged not to accept any provision which, in their view, falls short of what their child requires. Statements should concentrate on provisions rather than placement.

Δ Not knowing your rights

The 1981 Education Act makes provision for the full involvement of parents in the Statementing process. In looking at a child as a whole person, this involvement is essential. Unfortunately, many parents are ill-informed about the procedures of both assessments and the legally binding Statement of Special Educational Needs. Parents have access to the advice which professionals give to the LEA about their child and have the right to make known their views about them and appeal against the outcome. Many organisations can help parents and ASBAH is one of them. Remember that all parents should expect the best possible education for their child.

Δ Dealing with bureaucracy

Some parents feel threatened by bureaucracy, professionals and officialdom generally. Because of the assumption made that professionals know best, many feel that they are obliged to accept their advice and decisions. But sometimes one must challenge authority. In many cases officials are operating a bureaucratic machine which functions on fuel fed by policy making and financial advisers. People are not objects and must not be treated as such. Every case must be considered on its merits and not according to a generalised policy.

Δ Jargon used in Statements

Nothing is more offputting than receiving documents which do not make sense to you. Sometimes professionals, through force of habit, use words and/or abbreviations which are intelligible to other professionals but not to lay people. If this occurs then parents must seek clarification.

Also phrases may be misinterpreted because of indistinct meaning eg "John must improve his motor co-ordination". This statement could relate to a variety of experiences and skills. It is not specific in describing the real area in which the child has particular movement problems.

Δ Lack of co-operation between school and parents

It is very important that a good relationship exists between school and home. All too often problems arise because of mistrust and/or misunderstanding between parents and teachers. At case conferences, or general meetings, it is important that there is co-operation and not confrontation. In many cases fears and anxieties occur because there is a lack of information and understanding of the problems and needs of the child. In addition, there is often no clear school policy and support for pupils with special educational needs. It is important that parents and teachers regard themselves as partners in the education process.

Δ Teaching staff who don't understand the statementing process

Occasionally, teachers are not aware of the implications of the 1981 Education Act, and the need or relevance of a Statement. This is particularly so with hydrocephalus, when a child presents no physical disability but can exhibit what is unjustifiably defined by the teachers as laziness, bad temper or low intelligence. In many cases parents can help, together with ASBAH, by educating the educationalists about what is commonly termed "the hidden handicap". The problems experienced by children with hydrocephalus must be clearly defined on the Statement and readily understood by the teaching staff.

Δ Your child's teacher has not seen the Statement

It has been brought to my attention that teachers sometimes have to work with children with disabilities without real knowledge of their problems, because the headteacher has retained a copy of the Statement in the school office without a teacher having read it. Whilst it must be appreciated that a Statement is confidential it must also be recognised that its contents should be divulged to the educator if the child's interests are to be effectively met. Once again, effective dialogue and co-operation between the school and the parent can often overcome ignorance of the facts.

Δ Resources are not available to meet the needs specified

Speech therapy and physiotherapy are services which often fail to be given, even though mention of them has been made on a Statement. Children who need help to enable them to communicate fully with others, have a legal right to speech therapy. The 1981 Education Act requires LEAs to meet children's special educational needs, and speech therapy is one of them.

In 1989 a Court of Appeal ruling held that speech therapy was, in virtually all cases, an educational responsibility. As the Judges commented: "We do not see how to teach a child to communicate by speech can be any different from teaching him to communicate by writing: both are clearly educational". (X v Lancashire County Council 1989, Court of Appeal.)

All too often, physiotherapy, which is the responsibility of the Health Authority, is not available, although it is indicated on a Statement. An LEA sometimes regards physiotherapy as not being an educational requirement, therefore, it is included as a provision in Section 5 of the Statement. The LEA must provide educational provision under Section 3 (no matter what it costs) but there are no legal duties to provide services under Section 5.

What can you do?

To avoid the pitfalls outlined above the following steps are suggested:

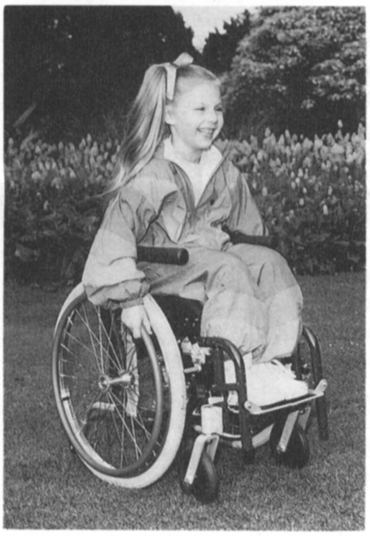
- Try to be involved as much as possible in the Statementing process by attending meetings, talking with professionals and contributing to the assessment of your child.
- Do not feel harassed or pushed into hasty decisions without prior consultation with friends or advisers.
- Elicit help when required concerning wording or phrases that you do not understand, or are concerned about.
- Do not allow great delays to occur in the assessment process. Do not hesitate to enquire what is happening or what stage the process has reached.
- Read all documents carefully and ask for help, particularly when things do not seem correct or explicit. (The education adviser at ASBAH or your local fieldworker will always assist if required).
- Try to maintain good relationships with the school, local education officers and other professionals whenever possible. They can often be your allies.
- Do not rely on verbal agreements. Always insist that everything is confirmed in writing and keep all documentation together with the date it was received.
- Remember that at every stage of the Statementing process, you have the right of appeal if you do not accept the conclusions and recommendations of the LEA.

Peter Walker, disabled living adviser (education).

PRODUCT NEWS

Items featured in product news have not been tested by us.

New wheelchair range



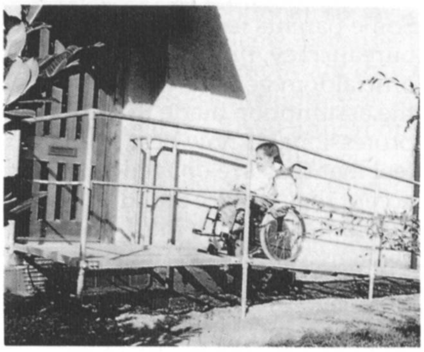
The choice of manual wheelchairs available for children has widened with the introduction of a child's chair as part of the new Suntec range from Sunrise Medical.

The Suntec Kiddie SX weighs 24lbs, and along with the adult version, has quick release wheels, fully adjustable rear axle plate and anti-flip stabilisers. It is available in various colours including neon pink, blue, yellow, red and black.

Both the adult and child Suntec SXs cost £750. More details on this range are available from Sunrise Medical Ltd, Fens Pool Avenue, Brierly Hill, West Midlands DY5 1QA, telephone 0384 480480.

Smooth Entry

Designed to be used for ease of access to either domestic or public buildings the Grorud Interchange is a modular ramp system.



It is made from galvanised steel and has adjustable feet and comes complete with handrails and raised kerb. Further information from Grorud Bison Bede, Castleside Industrial Estate, Consett, Co Durham DH8 8JB, tel: 0207 590149.

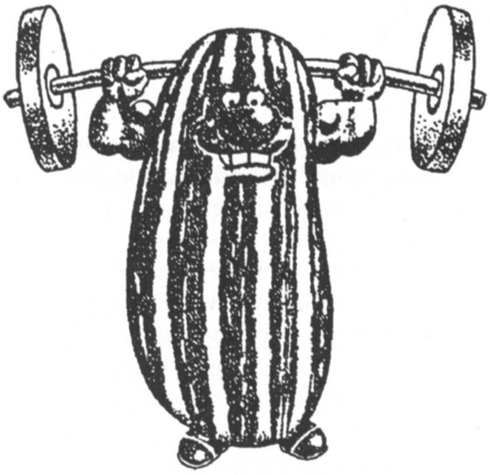
Merry Christmas

Leeds and Bradford ASBAH have joined with three local charities to produce this Christmas Card – monies raised from sales will be divided between them.

Middle Schools in the area ran a competition to design the card and this winning picture is by 13-year-old Liz Robinson.

Packs of 10 cards cost £1.80, orders to Mrs Anne Grange, Appeals and Activities Co-ordinator, Leeds & Bradford ASBAH, Five Oaks, Ben Rhydding Drive, Ilkley, LS29 8BD.

Nutrition and Spina Bifida



by Jane Williams disabled living adviser (continence)

ALL PEOPLE require a well balanced diet providing protein for muscle growth and maintenance, energy for growth and daily living, and vitamins and minerals for general health. These nutrients can be obtained from a variety of foods; meat, dairy products, cereals, vegetables and fruits. No food is a bad food, it is the amount and balance of food eaten that is important for health. For example, consuming too many eggs and too little fibre can lead to constipation. Consuming too many foods rich in energy can lead to obesity. Nutrition affects bowel balance, the urinary tract; skin state; energy levels and general well being.

PROMOTING HEALTHY CHOICES

Obesity is common in children with spina bifida, often occurring at the time a wheelchair becomes the main method of mobility. This is mainly due to a sedentary lifestyle. People with spina bifida have less muscle tissue because of the complete or partial loss of nervous tissue activity in the muscles of the lower trunk. As these muscles are not exercised, they shrink in size and less energy (calories) is needed than if these muscles are active. The energy requirement of a person with spina bifida, is about half of that of their able bodied peers and the amount of energy needed decreases with age, and women need less than men.

The problems encountered due to obesity can be wide ranging. Intermittent catheterisation and hygiene skills are difficult to perform - pressure sores develop easily. Mobility is more difficult and options for social development reduce, scoliosis and heart and lung functions are affected, all this can reduce independence and contribute to a lack of self esteem.

It is easy to see how the problem becomes compounded. Lack of mobility and self esteem means more time is spent at home in front of the television. Boredom leads to "snacking", rewards from parents and family tend to be high calorie sweet foods, and the child eventually becomes even more overweight, dependent and inactive. They may not appear to be over-eating compared to brothers and sisters, but in fact their nutritional requirements are quite different.

These contributing factors are complex, and may be very difficult to deal with. Neither a young person nor their parents should feel worthless or guilty if they are overweight. Remember, there are many able-bodied people who find controlling their weight difficult, despite having a higher calorie allowance!

ADVICE TO NEW PARENTS

Good habits start early in life; establishing a healthy diet early in life is the best method of preventing later problems such as obesity. A well balanced diet containing all the essential nutrients and including fibre and fluids - with an energy value within the requirements of the individual - is the best solution. If this is introduced from the very beginning and becomes a way of life for the child, it does not become an insurmountable problem later in life. The situation needs to be reviewed frequently, taking into account age, size and mobility.

Involve children in planning and preparing their own meals. This is often not done because accessibility is difficult. If they have an understanding of how to plan a balanced diet, and they are given responsibility and choice, then they are much more likely to succeed. Devise a system of rewards not based on food; games, music, books, outings, clothes, or just praising your child's appearance.

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WHAT IF I AM ALREADY OVERWEIGHT?

Working out a well balanced diet is not easy. People with spina bifida still need the same amount of protein, vitamins, minerals, fibre and fats (some vitamins are only found in fats) as other people, but they need fewer calories. Therefore, the foods chosen should be in the lower calorie range so as not to waste the calorie allowance. Ask your local dietrician to help you plan a balanced diet or join Weightwatchers.

There are several easy things you can do: use yoghurt instead of cream, semi-skimmed milk, lean meats, more fish and poultry, cut down on sweet things - such as cakes and biscuits, use low calorie drinks, and grill rather than fry food. Save sweets, crisps and chips for very special occasions. Make sure there is always a well stocked fruit bowl available.

Do more things that require energy - hobbies that require you to be out, and self propelling, sports and exercise. Exercise will not only use calories, but also develop the muscles of the upper trunk so that mobility becomes easier and self esteem improves.

A well balanced diet pays many dividends. Bowel and bladder management is easier, sores are less likely, mobility and self esteem improve. Being positive and responsible about nutrition helps to promote a much more positive attitude generally.

We at ASBAH understand the special needs of our client group and are ready to give advice and support.

Letters

Let them know you're coming

When she injured her leg on holiday in Ireland, continence adviser Mary White had to return home on crutches. Her experience on the ferry as a 'disabled' passenger prompted her to write to LINK. We publish an abridged version of her letter together with comments from Sealink and our own mobility adviser, John Naudé.

“Once on the car deck my troubles really started. On leaving the car I was wobbling down the narrow space between the vehicles. The amount of grease and oil underfoot made it positively treacherous and I was certain that I would not make it to the companionway without sustaining further injury.

When I reached the companionway, the sight of that vertical staircase was too much and I was close to tears. My daughter ran off to flash her eyes at a crew member and thus get help for her rapidly aging and infirm mother. "No problem", he said. "Go and tell your mother to come to the lift and we will take her up". The lift just happened to be at the other end of the car deck and to gain access to it one has to hop over a series of pipes which must be part of the water or ventilation system.

Distressed and exhausted, I eventually got there only to find that the layer of grease on the floor was even thicker than that on the car deck. At length we made for the restaurant. An expensive and unwanted waiter-served meal was the price gladly paid for pain-free space, peace and quiet. Relief was short-lived when the announcement came over the loudspeaker system, "Would all passengers please vacate the restaurant as the BBC wish to film a 'Jim'll Fix It' item.

There was no space anywhere by now except outside on the deck where I managed to find a seat in a spot too windswept and cold for anyone else. A kindly and rather embarrassed purser helped the family to get me there and promised to return, 'Jim'll Fix It' permitting, to help me to the car deck before the other passengers.

Please, Sealink, is it too much to ask for safe access and accommodation for disabled people, even if they are like me - just 'disabled for a day'. ”

A spokesman for Sealink told us that Mary's plight could have been avoided if she had let them know she was travelling on the ship. "If she, or one of her family, had called into the port office we would have ensured that her car was right next to the lift and have reserved seating for her." The spokesman went on to say that their policy is to "bend over backwards and if necessary hold up 629 cars to make sure a disabled driver or passenger gets on first to be near the lift". Though we did suggest that perhaps not all disabled people would want their arrival heralded in this way we did take the point that Sealink would make arrangements for expected disabled travellers - of course the public needs to be aware of this fact - and as John Naude, ASBAH's mobility adviser and a *wheelchair user himself, comments: "In an ideal world there would be no need to advise people in advance of your travel plans as all trains, boats and planes would be fully accessible to everyone, but until that day comes advance planning is necessary for the disabled traveller." John also used a Sealink ferry this year, on a different route, and when booking, told them of his mobility requirements. When he arrived his car was in the first five on board and parked by the lift and seating was reserved for him.*

oOo

So the moral of the story would seem to be - let the company know what you will need, then if they don't provide it you have every reason to complain.

No statement, thank you!

" I am writing to object about the article "A Statement Please!" which appeared in the August edition of LINK.

I have spina bifida and am currently in my fourth and final year of a BEd (Hons) science degree at Reading University. I have always been to mainstream schools and never received any special treatment (although I was limited in what I could do in PE and games). I have seven 'O' levels and two 'A' levels, all gained without the need for any extra attention from teachers.

Where would a statement have made any difference to my progress at school? I object to Mr Walker's statement that "all children with spina bifida and/or hydrocephalus should be statemented". If this is the case, every child in the country should be statemented as it is a fact that every child is an individual and therefore has different needs.

One other comment which I have to make is about the raising of large sums of money which is used to buy items such as battery operated tricycles for individuals. It seems to me that those who require such equipment are in receipt of mobility allowance and it is this which should be used to buy these tricycles.

I have just been turned down for mobility allowance (once again!) and have to run my car whilst living on only a student grant (I cannot do anything without a car) therefore I have to sacrifice other aspects of my life in order to do this - ie social life. It seems ridiculous to me that those receiving mobility allowance should "scrounge" when a year's mobility allowance would cover the cost of one of these tricycles. Meanwhile, people in a similar situation to myself have to get by quietly with no handouts whatsoever!"

Diane Grantham

Though Miss Grantham objects to our use of the word 'all' in the statementing article we do believe that all children should be assessed. Of course, this may reveal that a statement itself is not necessary. The statementing procedure is there to enable children with 'special' needs, be they physical or educational, to attend mainstream school by providing the resources/equipment required. Perhaps, if statementing had been available when Miss Grantham started school then extra provision might have been made to enable her to participate more fully in games and PE.

On the point about the use of mobility allowance, we would agree that it should be used for its intended purpose ie for a car, or powered wheelchair or for taxi fares, dial-a-ride etc but of course some people need both a powered chair or tricycle for indoor/local use and a car to enable them to travel further from home. We certainly do not agree that recipients of fundraising are "scrounging". Unfortunately equipment which is vital to disabled people's independence can be beyond the individual's pocket and not covered by any of the allowances and benefits to which they are fully entitled.

DIARY DATES

29-30 October: Special Needs Education Exhibition, Cumberland Hotel, Marble Arch, London. Admission free. Seminars on both days, admission by pre-booked ticket, £5.00 each. Tel: 071 580 6321 for details.

8-10 November: Perception - A Hidden Handicap. For teachers, therapists and carers helping children to cope with effects of spina bifida, learning difficulties etc. Tutor Pat Kennedy. Castle Priory College, Wallingford, Oxon. £148.50 inc accom. Tel: 0491 37551.

12 November: Continence in Spina Bifida - a study day for professionals - organised by ASBAH in conjunction with Oxford Health Authority. Radcliffe Infirmary. Fee £20, contact Heather Patterson 0993 776837 for more details.

26 November: Sex Education for All - Family Planning Association's major national conference at the Institute of Education, University of London, Bedford Way, London WC1. The fee is £69. Further information from the FPA, 27-35 Mortimer Street, London W1N 7RJ, tel: 071 636 7866.

27 November: 'Education Study Day' at ASBAH's National Office. Subjects include hydrocephalus and its treatment; learning difficulties and strategies for dealing with them; the role of the educational psychologist. Also workshops on specific problems. £40.00. Contact: Trish Jones, 0733 555988

November: Hydrocephalus Support Group Study Day at the end of this month in the north-east of England, date and venue details to be fixed. Contact Trish Jones at ASBAH for details on 0733 555988.

BOOK SHELF

The Great Ormond Street Book of Baby and Child Care

This claims to be "the authoritative, complete parents' guide to the first five years". Unfortunately, it fails to live up to this claim, despite its remarkable resemblance in size and weight to the bible! This is not a particularly 'user-friendly' book: the text is dense and uninviting; the line drawings approximate more closely to those of an old-fashioned medical text book and the black and white photographs give the book a dated feel. Some of the photographs are unclear and a "delivery by Caesarean section" is particularly uninformative and gruesome. Child health is approached from an entirely medical perspective and no consideration is given to poverty or poor housing as contributors to ill health.

Chapter 19 is entitled "Handicap" rather than disability and demonstrates an unfortunate lack of sensitivity to disability isues. The section on spina bifida is factually incorrect: "About five in every 2,000 children are born with spina bifida" - the OPCS figure is two per 10,000 live births. It is doubtful whether this section would be of any use to families who have a child with special needs.

Sections of the book dealing with child development and play stages might be useful for first-time parents, although the same information could be obtained from other cheaper and more interesting, colourful publications.

RS.

New from ASBAH

The Statementing Process for Children with Special Educational Needs is one of two new titles on ASBAH's publications list. It covers every aspect of the statementing process and is written by our educational adviser, Peter Walker. Price £1.50.

The other addition is *The Hydrocephalus Information Pack* which contains a selection of useful articles for parents, teachers and employers. Price £3.00.

Both items obtainable from Information Dept., National Office.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

HELP FOR MAINSTREAM AND SPECIAL SCHOOLS . . .AND FOR THE HOME

Hydrocephalus - a guide to Education

We have made a short video to help teaching staff, and possibly care staff, know more about how a child with hydrocephalus views the world - in and out of the classroom.

A child with hydrocephalus often experiences difficulties with visual perception, concentration, orientation and short-term memory. These symptoms are often misinterpreted by busy staff as laziness, clumsiness and sometimes sheer bloody-mindedness. But the basic problems are very real and, if not addressed early, can hinder development.

The video focusses on two main areas - hand-writing and number-work - and offers practical advice on ways in which these can be improved. It also stresses the importance of developing a partnership between school and home and of auditory stimulation. . . often with the child listening to his/her own speech.

We suggest strategies that can be adopted in the classroom which, if applied with determination, can help the child gain in confidence. The strategies are simple enough to be used in main-stream schools, usually with existing equipment. To help the child develop, the video shows how the lessons can be carried through to the home.

ASBAH wishes to thank the following for their special help and support in the making of this video:

The Department of Health

Zem Rodaway

The staff, parents and pupils of -

The Meads School, East Grinstead

Angmering School, West Sussex

Impington Village College, Cambridge

The video, 'Hydrocephalus - a guide to Education', can be obtained from ASBAH, 42 Park Road, Peterborough PE1 2UQ (tel 0733 555988 fax 0733 555985, registered charity number 249338).
Hire for one week is £5.88 + £10 deposit + 70p P & P, total £16.58 (inc VAT).

To buy, please send £30 + £5.25 VAT + 70p P & P, total £35.95. Cheques/postal orders should be made payable to 'ASBAH'.
Orders from overseas should be accompanied by cheques/ money orders payable in £ Sterling.
Please send all orders to Miss P Corns, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

Produced for ASBAH by Leonie Holgate MCSP SRP, Disabled Living Adviser and Tony Britton, Publicity Manager. Made by Monica Hart Productions © ASBAH 1991

ADVERTISING

FOR THE USE OF LOCAL ASSOCIATIONS AND OTHER READERS

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

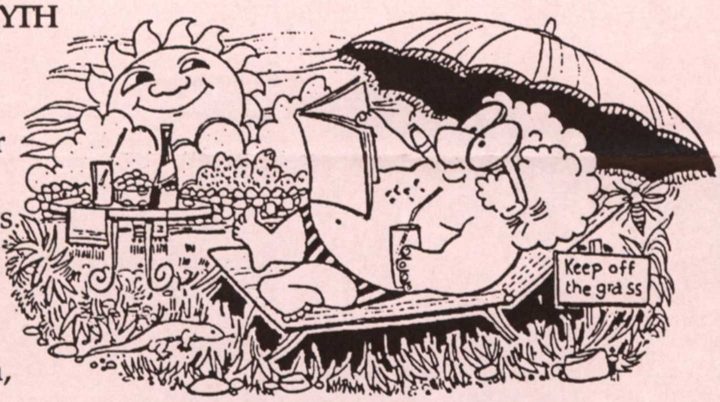
Small adverts for the next issue of Link (December) should be submitted by Friday, 8 November. Please send them to: The Editor, ASBAH House, 42 Park Road, Peterborough PE1 2UQ.

HOLIDAY ACCOMMODATION

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

BORTH NR ABERYSTWYTH

Six berth caravan. Suitable for large wheelchairs. Licensed site. Five minute walk to sea, shops etc. Details: Mrs J Carter, 1 Meadow Road, Craven Arms, Shropshire SY7 9QY



ISLE OF WIGHT ASBAH

Completely refurbished, fully equipped, wheelchair accessible, 2 bedroom holiday chalet, sleeps 6 plus cot. Clubhouse, indoor heated pool, shop, etc. Site overlooks sea. Own transport advisable. Details from Mrs P Burden, 36 Sherbourne Avenue, Binstead, Ryde PO33 3PX

WINTERTON-ON-SEA, GREAT YARMOUTH, NORFOLK

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

HAVING DIFFICULTY lifting your child in and out of a wheelchair? I have designed a special seat and system which can help. For details ring Dave Lawrence on 0255 675245.

GOWRING CONVERSION MINI (Blue) X Reg. Mileage 24,000, very good condition. Fitted with high roof, lowered platform and ramp, £1,900. Phone Mr Cope on 0522 753402.

LOOK INTO THE FUTURE TODAY

LIFT

The magazine for young ASBAH members

This month:

- New Divison for Basketball
- Look at Guiding
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...and there's more.

To get your FREE copy 'phone Lyn or Rolanda on 0733 555988

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