

Link

Association for Spina Bifida and Hydrocephalus/ASBAH 20p

Nov/Dec 84



A happy family enjoying the snow in Norway . . . but it hasn't all been smooth going — the little girl on the right, Ann-Karin, was born with spina bifida and hydrocephalus and doctors didn't give much for her chances. For the full story see page 17.

HAPPY CHRISTMAS

ASBAH to host the 1985 International Conference: Investing capital for your children's benefit: Bowel management: Car seating: ANNUAL REPORT: LINK visits the Fortune Centre.

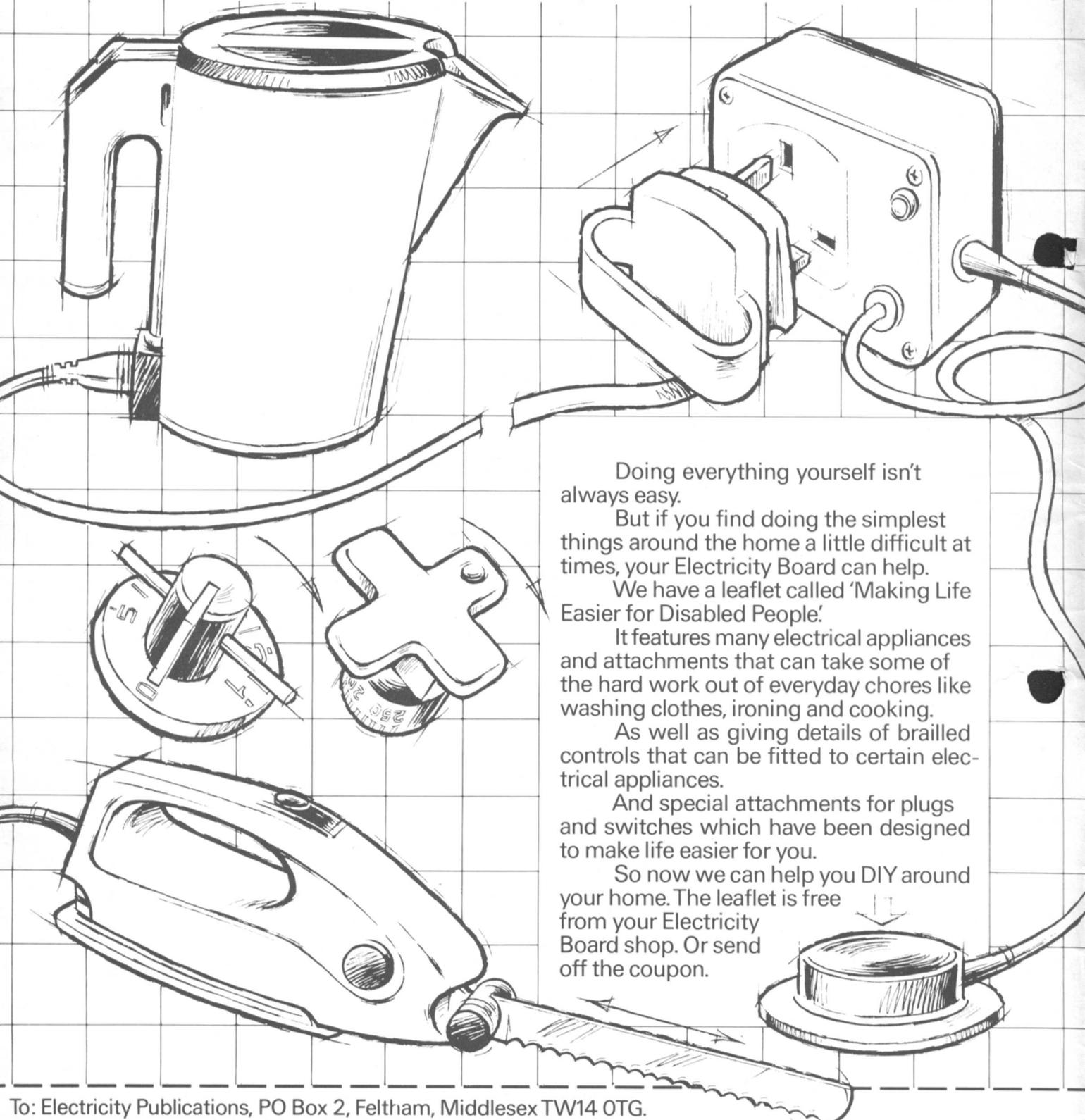
Inside: Guidelines for Local Associations No. 2.



LINK 95

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Association for Spina Bifida and Hydrocephalus/ASBAH

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Tel: 01-388 1382/5

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

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A Year for Participation, Development and Peace

NEXT YEAR is International Youth Year. The United Nations has made 1985 the year when it hopes the needs and aspirations of young people throughout the world will be promoted.

As with previous 'special' years, like the Year of the Disabled in 1979, the UN hopes that youth issues will be recognised as of major importance by the end of 1985. The hope is that young people will be seen to play an important contribution in shaping their own futures and those of their communities.

One fifth of the world's population is aged between 15 and 25. And it is this group that the UN is focusing on. In parts of the developing world, this proportion is expected to rise dramatically over the next 20 years.

In Britain, the problems of unemployed young people will be a priority, as will the integration of disabled young people through equal opportunity and greater understanding.

Three themes have been set out for the year: *Participation, Development and Peace*. With participation, which the British Youth Council has long promoted, youth will be encouraged and enabled to make the decisions which affect their lives. Adults should take a back seat — as advisers. With the right back-up, young people have an enormous contribution to make to society.

Secondly, young people will be encouraged to develop. This means understanding themselves, their potential and the processes of maturing.

And thirdly, peace is vital to the future of young people everywhere. Both personally and in the community young people can learn to resolve conflicts. Inner conflicts, and conflicts which better understanding of racial, cultural and religious differences can overcome. Of course, the misunderstanding which society has of the handicapped is one of these conflicts which we hope young people will overcome.

Greater comprehension of the role of young people should be the result of the year — in the UK and internationally. This understanding should involve their difficulties in relation to jobs, education and training, housing, the police, disabilities and inequalities.

There are four IYY Co-ordinating Committees in the UK. They serve England, Wales, Scotland and Northern Ireland. Made up of young people and adults, working together to develop an approach broad enough to encompass the diversity of young people's aims and aspirations, it is hoped they will make 1985 the beginning of a plan for their future which is lasting.

And that is something which we in the British Youth Council would greatly welcome.

For further information on International Youth Year contact:

IYY England, 57 Chalton Street, London NW1 1HU — Tel 387 4777

IYY Scotland, Atholl House, 2 Canning Street, Edinburgh — Tel 031 229 2433

IYY Wales, 27 Church Road, Whitechurch, Cardiff — Tel 0222 615932

IYY Northern Ireland, 86 Lisburn Road, Belfast, Northern Ireland BT9 6AF — Tel 0232 681477

CONOR RYAN

Communications Officer for the British Youth Council.

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



LEEDS United fan, Luke Clayton, photographed outside the Elland Road ground with Manager Eddie Gray, on a never-to-be forgotten day when Luke met his heroes. The outing to Elland Road was arranged by Luke's headmaster, Mr Derek Sykes of Kitwood Boys School. Luke who has spina bifida has long been a supporter of Leeds United. Luke, his headmaster and Luke's parents, Peter and Eileen, were shown around the Elland Road ground, visiting the dressing rooms, boardroom, the dugout. They saw the trophy cabinets and were then introduced to the players by the manager, Eddie Gray.

Faith steers her way to a win

CONGRATULATIONS to Faith Seward, a member of ASBAH's Executive Committee, who won the manoeuvrability section of the Institute of Advanced Drivers Driver of the Year Competition in York recently. The test involved car handling, driving between cones, reversing, parking and general car control.

There were 54 entrants in the section and Faith won driving a hand-controlled Triumph Acclaim. She has been a member of the Institute for 10 years. For her endeavours Faith was presented with an inscribed carriage clock.

Fund aims to help youngsters

A NEW fund has been started to provide financial assistance for young people wishing to go on ASBAH courses.

Mr Dennis Bryant, Executive Committee Chairman, announced at the Annual Meeting, the setting up of the Professor Lorber Bursary.

Prof John Lorber, one of the founders of ASBAH, has decided that he would like to establish a bursary especially for young people. In view of the importance of the various ASBAH courses, he felt it appropriate to provide a fund to finance any young person with spina bifida and/or hydrocephalus who would like to go on one of the Courses and who is having trouble getting assistance.

Applications for any young person should be made to Miss Moyna Gilbertson at National Office.

The Bursary is open to donations so that it can continue over many years to support young people in this way.

International Conference

ASBAH is hosting the 1985 Conference of the International Federation for Hydrocephalus and Spina Bifida at the University of Manchester Institute of Science and Technology (UMIST) September 25-28.

In addition to an interesting Conference agenda, an exciting day out is also being planned. UMIST is an accessible venue, within easy reach of main line stations and Manchester Airport. Space will be available, at no extra charge, for local associations attending the conference who wish to mount displays. Please contact Paul Dobson at National Office for details.

A programme, full Conference details and the cost per delegate — which is not likely to be more than £150, will be available soon from National Office, and will be circulated to all local associations.

It looks like being a stimulating Conference and it is hoped that as many ASBAH members and friends as possible will be there.

LIFT WEEKEND

THERE'S sure to be a rush for LIFT's second Weekend. The first one proved very successful. If you hurry you might still get in!

The Weekend is to be held at Owen's Park, Manchester, as before, between March 29-March 31. It is for anyone with spina bifida and/or hydrocephalus aged over 14.

The programme is now out and there is a good mixture of informative debates, workshops, speakers, and — wait for it! — a play/farce with a message. For full details contact LIFT Office, 22 Upper Woburn Place, London WC1H 0EP.

Young visually handicapped

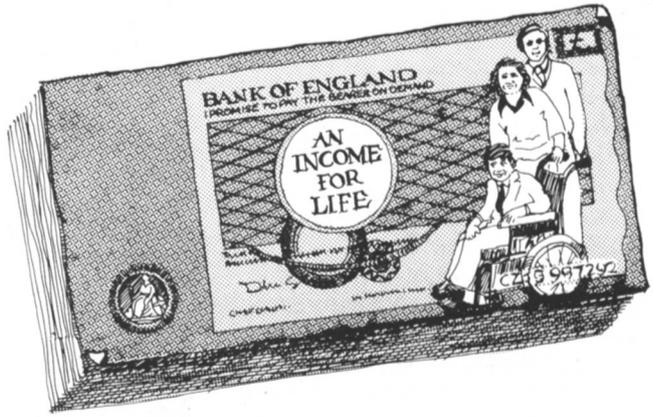
A COURSE dealing with the early training and education of visually handicapped children is being held at the Spastics Society college — Castle Priory College, Thame Street, Wallingford, Oxon (Tel: 0491 37551) from January 7-10. Entitled "The Young Visually Handicapped" it is aimed at all staff working with children who have little or no experience of visual handicap.



Christopher Paul, of Kent Association, holding the much coveted UEFA Cup. It came about because Christopher was watching a match between Tottenham Hotspurs, the Cup holders, and Southern League Gravesend and Northfleet. He entered a quiz in the match programme . . . the prize for which was to be photographed with the Cup. He was 'over the moon' when he heard the announcement at half time saying he had won. As well as the photograph he got a programme autographed by the Spurs players and two tickets for the next match.

THE THIRD in a series of articles by John Taylor on making financial provision for your children.

Now, here are some capital ideas



HAVING dealt with our children's security in the event of the loss of a parent in previous issues of *LINK*, this article gives some ideas of accumulating or investing capital for their benefit, thereby giving them more independence.

Building Society

THIS is an ideal place to keep "rainy day" money. That is to say cash that may be required at short notice in an emergency or for holidays, Christmas, etc. Also, if a mortgage is required in the future a building society account is a 'must' as very often societies will only consider lending money to an existing customer.

Usually the amount of money invested is not taken too much into account when considering a loan.

This means not all the client's money need be in the account — indeed, historically, it may not have been a good idea to put all available cash into a building society. It has only been over the last few years that the interest has kept up with inflation, let alone seen any real growth.

The interest is paid net, that is tax-paid at the 30% rate. If the client is not a taxpayer he cannot reclaim the tax paid by the society.

Banks

CURRENT bank accounts are most useful for paying bills but not, as a rule, for saving money. The other type of account, deposit, does attract interest but it is usually lower than that earned from a building society. At present the interest is paid gross, this means that the client is liable to pay tax if his income is taxable.

In some cases the return can be better than a building society depending on the client's tax position and the rate of interest at the time.

Premium Bonds

AN IDEAL home for "flutter" money: no interest is paid here but there is the CHANCE of winning a cash prize. Obviously it is not the best way of achieving a lump sum in the future but it could be worth buying a few bonds as your number may "come up".

Insurance Linked Investment Plans

THERE are ways of investing in the true sense of the word that do not require large amounts of money but do offer the opportunity to obtain the same growth prospects that, in the past, were only available to the wealthy. I refer to the modern insurance linked investment plans that most companies offer linked to one or more investment funds.

Although there are specialist funds to choose from there is normally a managed fund that can be linked to

your plan. This is looked after by the investment managers and the responsibility of watching the various markets is lifted from the client.

By investing in such a plan you will benefit in the growth experienced by the fund. In the past this growth has exceeded the interest given by both building societies and banks and has been a hedge against inflation.

The money invested in this type of plan is not so accessible as that in a building society. To my way of thinking this is a good thing. It is more likely to become a substantial cash sum in the future than, perhaps, it would elsewhere.

Tax Relief

THE SNAG at this time with an insurance linked plan is that tax relief is no longer available on the contribution; it was abolished on new plans in the 1984 budget. Prior to last March a subsidy was available from the Inland Revenue which made these plans very attractive. The charges made by the insurance companies was amply set off by the 17½% subsidy.

However, all is not lost. There is still a way of obtaining tax relief of at least 30% on contributions.

It works in very special circumstances that may apply to your child. Should you have a child who is over 18 and you "promise" to give him/her a set amount of money each year then your child should be able to claim back the tax that you have paid on the money when you earned it. This means that if you gave £200 a year then your child could invest £200 plus the tax reclaimed, £85 if you are a standard taxpayer, making a total investment of £285 p.a. This will only work if your child does not earn enough money to pay tax.

Although you have "promised" to give a set sum for at least 7 years you may stop gifting at any time. This method of obtaining a tax subsidy is by the use of a covenant set up by the client and the company and is not so complicated as you may have thought.

Should your child be under 18 and single then the parent cannot use this method but a grandparent could. If you want to know how this scheme could work for your child I suggest you contact me through ASBAH.

I am suggesting that the investment plan is taken out by your child on his/her life. We know that being disabled can preclude people from obtaining life assurance. However, it is probable that a company will

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CHILDREN and adults with spina bifida are frequently troubled by faecal incontinence, yet patients with spinal cord injuries, who have similar damage to the nerve supply of the bowel, rarely experience this problem.

The most important reasons for this discrepancy are:

- management of the bowels in patients with spinal cord injuries is logically related to the way in which the nerve supply is damaged,
- these patients are properly instructed in the practicalities of bowel care,
- treatment is begun from the time of injury and not delayed until over-distension of the bowel makes management more difficult.

It has been my experience that the methods used by spinal injury units for many years can be applied with equal success to spina bifida patients.

The objective is to have bowel actions when, and only when, the patient wishes and to have no soiling in between. An evacuation every day is ideal, but one every 2 or 3 days is sometimes acceptable. Actions less often are undesirable since they lead to over-distension of the bowel.

To understand the principles of bowel management requires some knowledge of the relevant anatomy and physiology; readers interested only in the purely practical aspects should disregard the following section.

Principles of Bowel Management

Muscle in the bowel wall contracts to move faeces onward while the muscle ring around the anus (anal sphincter) contracts to retain faeces in the body. Mass onward movement of faeces tends to occur after meals (the gastro-colic reflex) and especially after breakfast. Despite lack of pelvic sensation, many spina bifida patients are aware of these movements.

The contractions of the bowel and anal sphincter are dependent on their nerve supply. In patients with spina bifida this is normal except for that to the lowermost part of the bowel (the rectum) and to the anal sphincter. The nerve supply to both these structures comes from the lowest part of the spinal cord.

As with other muscles in the

Bowel Management for Patients with Spina Bifida

A. M. K. RICKWOOD
Urological Surgeon, Alder Hey Children's Hospital, Liverpool.

body, these nerve connections to the spinal cord take the form of reflex arcs (Fig. 1) and in patients with an undamaged spinal cord, the reflexes are controlled by nerves travelling down the spinal cord (Fig. 1, x) from the brain. In spinal cord disease, the integrity of this system can be disrupted in two ways.

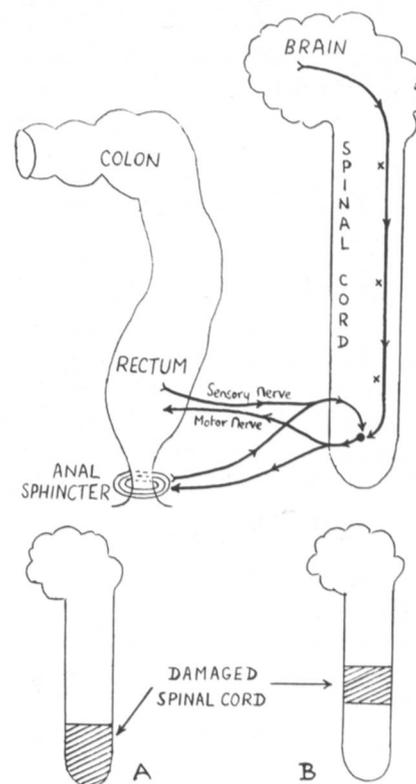
Firstly damage to the lowermost part of the spinal cord destroys the reflex arcs (Fig. 1, A) and in consequence there is complete paralysis of the rectum and anal sphincter. The rectum cannot contract to expel faeces nor can the anal sphincter contract to retain faeces. This type of damage occurs in some two thirds of spina bifida patients.

Secondly damage at a higher level may leave the lowermost part of the spinal cord intact but isolated from the brain (Fig. 1, B). The reflex arcs are still present and appropriate stimuli cause reflex contractions of the rectum and anal sphincter.

The type of damage can be deduced from the *ano-cutaneous reflex*. A pin is stuck into the skin around the anus (having first made sure the patient has no sensation in this area!). If this causes no contraction of the anal sphincter, the reflex is negative and spinal cord damage of the first type is present. If the anal sphincter does contract, the reflex is positive and there is damage of the second type.

Practicalities of Bowel Management

The type of treatment is determined by whether there is, or



is not, an *anocutaneous reflex*.

Patients with Negative Anocutaneous Reflex

The problems in this group are that:

- the rectum cannot contract to expel faeces,
- the anal sphincter cannot contract to retain faeces and pressure-rises in the abdomen caused by standing, coughing, laughing etc. tend to cause leakage of faeces.

Faeces may be removed from the rectum by:

- abdominal straining (deep breath in, hold and bear down); this is only possible for patients old enough to co-operate and who have abdominal muscles which are not paralysed,
- pressing over the lower abdomen (expression),
- manual evacuation of faeces with a gloved finger in the rectum.

One or other of the last two methods must be used in infants and also in patients whose abdominal muscles are paralysed. Manual evacuation is definitely more efficient than expression. Some patients who use abdominal straining to defaecate cannot completely empty the rectum by this manoeuvre and should use manual evacuation to complete the process.

Any of these methods is best carried out soon after a meal when

the gastro-colic reflex has filled the rectum. Patients are often aware when this has occurred. It is usually necessary to evacuate the bowels daily to avoid soiling.

Suppositories of any kind are useless and usually drop straight out into the toilet. I never cease to be amazed how patients mis-advised to use suppositories continue to do so for years on end despite their very evident lack of any useful effect.

The motions should be bulky and firm so that they do not 'drop' through the paralysed anal sphincter and for this reason high residue diets are best avoided. Trial and error will disclose those items of diet which result in loose faeces. Firm faeces also make for easier manual evacuation.

Patients with Positive Ano-Cutaneous Reflex

As a rule, this minority of the spina bifida population should find bowel management comparatively straightforward. Evacuation of the bowels is achieved by some stimulus which provokes a reflex contraction of the rectum. Weakness of the anal

Bowel Management

sphincter is not a problem; indeed pressure rises in the abdomen cause reflex contraction of the sphincter.

Reflex contractions of the rectum are most conveniently obtained with a Dulcolax (bisacodyl) suppository, 5 mg for under 2-year-olds, 10 mg otherwise. Other suppositories (such as glycerine) do not have this effect and should not be used.

If a Dulcolax suppository does not produce a complete bowel evacuation within 30 minutes, the more potent Dulcolax rectal solution (1-2 ml) may be tried instead. Again, Dulcolax is best given soon after a meal, but it is often only required on alternate days. Occasionally Dulcolax is not effective and manual evacuation must be used in this circumstance.

Because weakness of the anal sphincter is not a problem and because the rectum contracts more efficiently when the motions are soft, a high residue diet is advisable.

When To Treat And How To Learn

Far more often than not, parents

of babies with spina bifida receive no coherent advice on bowel management. As long as the bowels open somehow and sometime (as happens if nothing at all is done) no one is concerned until later when faecal incontinence becomes a social problem.

By then, this policy (or lack of it) will have led to over-distension of the bowel which makes subsequent management appreciably more difficult. There is much to be said for starting treatment early in infancy; even as young as this, testing for the ano-cutaneous reflex will show what is required.

The use of suppositories or rectal solution is simple and requires little instruction. The prospect of manual evacuation of faeces is somewhat daunting for parents and appears to inspire feelings of positive dread in the minds of many of their advisers with the result that it is either not done at all or is performed in such a pussyfooting manner as to be quite useless.

Manual evacuation must be done vigorously and thoroughly and

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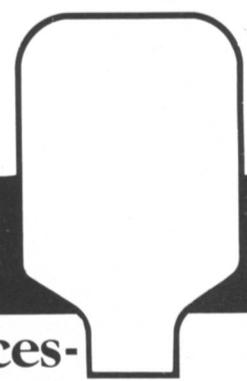
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*Continued from
Page 7*

those who advise on bowel management should be able to teach the technique properly. Parents are often apprehensive of causing internal damage but may be assured that this is highly unlikely. Certainly manual evacuation is unpleasant, but is a great deal less so than constantly dirty nappies or underwear.

For some inscrutable reason family doctors frequently inform parents that the disposable plastic gloves used for manual evacuation are not available on the National Health Service. This is not so; they are supplied free of charge on prescription from any general practitioner.

Many older children learn to manage their bowels independently, but those severely handicapped by restricted mobility, a major spinal deformity or the effect of hydrocephalus may never achieve this. Regrettably as this is, it is no reason why correct bowel management should be neglected by their helpers.

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from
Page 5*
**Now
here
are
some
capital
ideas**

**Copy
date
for
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Dec. 5**

issue a short term policy with reduced life cover. This should not affect the investment element.

Should your child be over 18 and earning in his/her own right then a covenant may not be possible as a way of obtaining tax relief. Another way of achieving this could be via a personal pension plan. If your child is not in a company scheme then it is an option open to him/her.

Tax relief is obtainable on contributions to a pension scheme at the top rate of tax. I would stress that a pension plan is a long term investment that cannot be drawn upon until retirement. It may still be a good idea as our children are as likely to retire as we are.

There is no medical requirement to enter a pension scheme and the benefits include a lifetime income in retirement and a tax free lump sum. Anybody starting a plan whilst young could expect the cash sum to be at least equal to the amount they have paid in, perhaps more, plus a "free" pension for the rest of their life.

I will say again that this is not a short term idea but one worth consideration as the ultimate benefits are very good.

I have endeavoured to outline some possibilities you may want to consider as a way of allowing your children to have a more secure financial future and subsequently more independence. I will be pleased to receive any comments or questions about the suggestions made through ASBAH, in particular those relating to covenants.

**With this LINK — the second Guidelines
for Local Associations — *Administration***



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The safe driver needs a comfortable seat

THE MORE I become involved with driving for the disabled, and in particular with the spina bifida group, the more I realise how crucial is correct and comfortable seating.

I was privileged to take part in the first Lift Conference in Manchester. This proved to be both interesting and thought provoking. I was very willingly assisted by my husband, Derek, in demonstrating a Ford Escort fitted with hand-controls and various other attachments designed to assist the disabled person.

Apart from other considerations, the difficulty that the majority of the young people had when sitting in the driver's seat, was seeing out. This was not a fault of the Escort design, as the same would have applied to any other production car.

Many people with spina bifida have some bony defect in the spine which results in short sitting stature. This may be accompanied by instability in the trunk because of weakness in the neighbouring muscles. Therefore, they are sitting low and insecurely in the driver's seat.

The easy answer to this is "give them a cushion to sit on" but I do not think that this is the wisest solution. It is not only a question of loss of height but may also involve the angle of the seating, the proximity of the seat to the controls, the support and comfort of the seat and last, but by no means least, the safety of the seating.

Firstly let us consider what the seating provides and then discuss ways in which adequate and safe seating may be achieved.

Visibility

There must be good all round vision out of the car and, therefore, the seat must be the correct height.

The driver should not be peering through the wheel or banging their head on the roof at every bump in the road.

Stability

The driver should feel secure within the seat and not have a sense of uncertainty and a need to "hold on", particularly if using hand-controls. This instability may be felt when the car is cornering or doing any sharp manoeuvre.

Ability to Reach All Controls

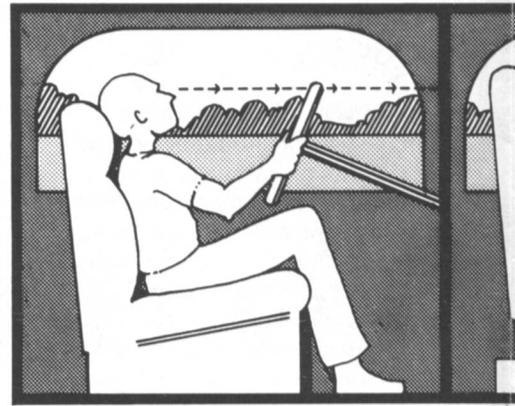
These days, as a rule, most of the secondary controls (indicators, windscreen wipers, dip switch, etc.) are arranged around the steering column but some may be located on the dashboard. For drivers using hand-controls, there is extra strain on the shoulders because the arms are active all the time to a much greater extent and it is important that the controls are within easy reach.

Comfort

This is not a luxury, but a necessity. If the driver is not comfortable his attention will not be, entirely, on the road and the control of the car. There is another important aspect for the person with spina bifida. They may have anaesthetic areas of skin and so require extra attention to the moulding and the fabric of the seat. The question of comfort involves the angle of the seat. The rear only of the seat may need raising. If the entire seat is raised, the steering wheel may rub on the legs or lower abdomen. This could be both unpleasant and dangerous for anaesthetic skin. The illustration (above) makes another important point. The feet must be well supported and not allowed to dangle.

Safety

If the seat has to be modified in



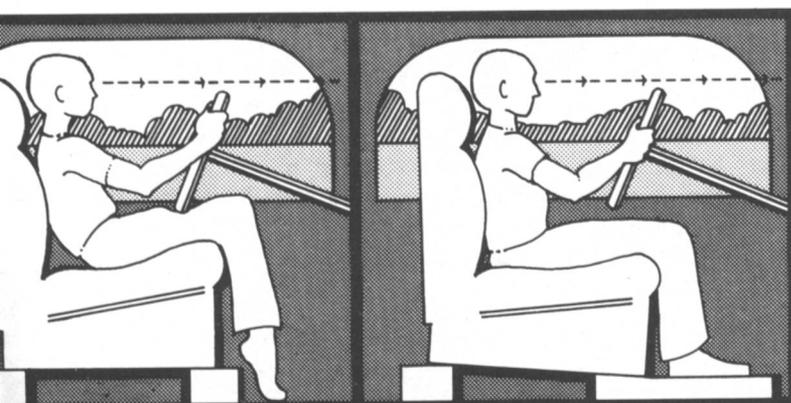
1. Too low

2. Too high

any way, the way in which it is done is very important. Any old cushion plonked on top of the seat is definitely not good enough. The cushion may slip causing loss of concentration and ability to see adequately; in an emergency stop it could slide off the seat altogether and the seat belt could cut into the abdomen at an incorrect level causing very serious injury. An insurance claim may be invalidated because a loose cushion would not be acceptable as adequate and safe seating. This innocent cushion could mean a fatal or very serious accident for the driver, passengers or other road users.

Here are some ways adequate and safe seating may be achieved

- When buying a car, definitely shop around. Get in and out of the car, wriggle around in the seat and ask to have a test drive. The passenger and driver's seat are usually identical. Take time in choosing and, if the seat is going to need modification, check with the conversion specialist, before actually purchasing the car, that this will be possible on the particular model.
- The most secure way of raising a seat is to do it from beneath with adjustable pillars or similar device. These can be altered for other drivers and removed altogether when the car is sold. Thus the angle of the seat can be corrected as well. If lessons are being taken on an instructor's car, it will not be possible to make structural alterations and some other means of adjustment may have to be made but it must be *safe*.
- There are several booster cushions on the market for raising



too high

3. Correct height

the level of the seat. These are mainly for children but some of them would be suitable for the small adult. Back supports may also be used to bring the driver forwards when the squab of the seat appears to be too long. Many people with spina bifida have short legs and they may require an insert to be positioned in the well of the car to support the feet.

The key to success for any of these devices is their security and they should all have the means of firmly fastening them and this should be checked. A cushion may be custom made using foam with a suitable covering and straps incorporated to hold it securely in position. The local occupational therapy department would probably be able to help with this.

- Side supports and/or a racing style harness can provide stability for the driver. Many people with spina bifida have weak trunk muscles below the level of the lesion and this means that they are unstable when any lateral or fore and aft forces are applied as in cornering or an emergency stop.

When sitting in a wheelchair there is support from the arm rests and very often these are used unconsciously to give support when using the hands. One arm may be used to steady the trunk while the other arm is working or the elbows rest on a table or bench and the hands are then free to perform a task. When driving a car using hand-controls both hands will be fully occupied and there will be no table or bench on which to lean. However, removable arm rests can be added to the car seat giving lateral support and on which the

arms may rest while operating the controls.

A sudden stop or jolt may cause the body to flip forwards and this is particularly so where there are no muscles to counteract this force. A racing driver type harness gives much more security to the whole trunk and to the person themselves, enabling them to relax and concentrate on their driving. Racing drivers use them for this reason and they are probably submitting their bodies to similar forces as normal driving would exert on paralysed or partially paralysed spines.

- Neck rests and rear vision mirrors are very closely linked with seating and should be mentioned. To some extent head or neck rests are a personal choice but they do help to minimise or, possibly, prevent whiplash injuries. With people of short trunk stature the seat will provide the neck rest as well. This can interfere with rear vision and the ability to check the blind spot.

Adequate coverage of these areas is essential. This can be by means of internal and external mirrors (panoramic rear-vision mirror and wing mirrors and any other mirror angled to increase the range of vision). When hand-controls are being used, it is not easy or always advisable to twist in order to reverse the car.

Conclusion

Many of the aids to adequate and safe seating such as cushions, safety belts and mirrors can be purchased from a good car accessory shop. Before making a decision on any article, ask to have it on approval and try to have a good run using it, ie, an hour or more of driving. This

Article by Leonie Holgate

Mobility Adviser, based at Banstead Place

should indicate whether the cushion or the back-rest, for example, is really going to be what you require.

With other articles, such as seat belts or mirrors, this may not be possible because they need fitting to the car but do ask around and seek expert advice from your local conversion specialist, if you have one, or from one of the addresses at the end of this article.

It is advisable for the disabled driver or the parents of a disabled person to join the Disabled Driver's Motor Club and the Disabled Driver's Association and to purchase a copy of "Motoring and Mobility for Disabled People" published by R.A.D.A.R. These keep the reader or member up to date on all the latest gadgets and safety equipment and are a fount of information. Banstead Place Mobility Centre will answer any queries by phone or correspondence and they also give driving ability assessments and car adaptation assessments.

May I wish you safe and comfortable motoring.

The following is a list of useful addresses.

Disabled Driver's Motor Club, 1a Dudley Gardens, Ealing, London W1N 8AB. Tel: 01-637 5400.

Disabled Driver's Association, Ashwellthorpe, Norwich NR16 1EX. Tel: 0508 41449.

Banstead Place Mobility Centre, Banstead Place, Park Road, Banstead, Surrey. Tel: Burgh Heath 51674.

Mobility Information Service, Copthorne Community Hall, Shelton Road, Shrewsbury, Shropshire SY3 8TD. Tel: Shrewsbury 0743 68383.

"Motoring and Mobility for Disabled People" by Ann Darnborough and Derek Kinrade, R.A.D.A.R., 25 Mortimer Street, London W1N 8AB. Tel: 01-637 5400.

1984 ANNUAL MEETING

THE WESTMINSTER Cathedral Conference Centre in London proved a very suitable venue for ASBAH's 18th Annual Meeting – the third time the meeting has been held here. About 100 ASBAH members from all over the country attended the Meeting, and took full opportunity of this chance to meet together and exchange news and views.

ASBAH's 'coming of age' this year was marked by a bumper Annual Report – a new size and a new style which draws attention to ways in which ASBAH has developed since its inception. Copies are obtainable from National Office.

The Meeting was presided over by the Executive

Committee Chairman, Mr Dennis Bryant, in the absence of Lord Maybray King. Mr Bryant expressed the meeting's regret that Lord Maybray King was unable to be there because of ill-health and sent his best wishes for a speedy recovery.

A particularly welcome friend at the meeting was Lady Coggan, one of ASBAH's Vice Presidents. She had the pleasant task of accepting a £1,000 cheque on behalf of ASBAH from Mrs June Davies of Staffordshire's Local Association. This handsome donation to ASBAH's work nationally has become an annual project for this local association.

Shaping up for the future

IN HIS opening remarks, Mr Dennis Bryant, Executive Committee Chairman, explained some of the changes that have taken place in the committee structure at National Office.

He said: "We have tried to give a different shape to the Association in this 18th year. The idea was to set up bodies that would more directly and accurately reflect the Association today and cut out repetition and so many time-consuming committees".

There are two major decision-making committees – Finance and General Purposes, and Services – reporting to the Services Committee are a number of Working Parties which have enabled ASBAH to use the help of outside experts. Mr Bryant also explained that the Medical Advisory Committee continues to vet research proposals and offers specialist advice to the Executive as and when necessary.

"The new system has only been going for a year which is a short time to assess its effectiveness, but I think it is working well. We have found it a more straightforward structure to operate", he said.

Mr Bryant also referred to another change in the Association – the retirement of Mr Frank Armour from the position of Finance Director.

He said: "Frank has had a longer, continuous, association, working for ASBAH than any other individual – 18 years – right from the inception. He was Honorary Secretary for two years, then became a member of Executive, and first Finance Officer.

"Frank has found it time to have a lower profile. With the growth of the telesales operation, that activity has needed help on the financial side. Frank has moved over to work there, and we extend our gratitude to him for all his work over the years".

Mr Bryant welcomed the new Finance Director, Mr Derek Knightbridge.

In referring to the wide ranging work of ASBAH, Mr Bryant said that the most significant event of the year was the first LIFT Weekend.

On a more worrying note, Mr Bryant said the deficit incurred by ASBAH during the year was giving cause for grave concern.

All set for new challenges

THE ANNUAL Report was presented by the Executive Director, Miss Moyna Gilbertson.

WE HAVE been particularly concerned to project the 'growing up' image of the Association and its work and we are now ready to launch in to new areas of activities, particularly expanding our involvement in accommodation and employment.

It seems appropriate, therefore, that during this year we have also moved offices. The immediate reason for this was to enable us to enlarge our fund raising department to attract the vast sums of money now necessary in order to fulfil our programme. During the move we have learnt a considerable amount about tolerance, not least because of the appalling delays by British Telecom.

I would like to thank everybody for being so patient, both those trying to contact the office and the staff for working under considerable difficulties for more than six months. The DHSS helped by giving us a supplementary grant to buy furnishing and equipment, and, carpet tile laying can now be added to the skills of ASBAH staff and their friends.

The activities of LIFT and the development of services for young disabled people is becoming steadily more integrated with our membership of the International Federation for Hydrocephalus and Spina Bifida. Three delegates from Norway attended the LIFT Conference. Mr Chris Hopkins, Chairman of the LIFT working party has been to Germany to study centres where young disabled people live, study, work and play.

ASBAH is about to represent the Federation at a meeting in Brussels to discuss services for disabled people.

This is all leading up to the International Year of Youth 1985 and as part of the planning process ASBAH is a member of an informal consortium of charities which will co-operate in the organisation of events for the year and endeavour to avoid duplication of effort. One of the major events during

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the year will, of course, be the LIFT Conference.

There are more courses for young people at Five Oaks which has already held one fashion course, supported by the EEC.

A second course was starting that evening. Another LIFT Activity Holiday has just finished at the Calvert Trust.

You will possibly have noticed in the Annual Report reference to our involvement with the MSC Community Programme, in order to extend our field works services. This is proving very successful in some areas but unfortunately we are encountering problems in others and the schemes are not as well forward as we had hoped.

As we have reported previously we are very aware of the need to provide a personal counselling service and have tried several systems. Our current thinking is that the most efficient way is to establish a register of counsellors who work on a consultancy basis. So far we have enrolled seven counsellors and hope that another will join the scheme very soon.

One of our pre-occupations is to think of ways to reach a greater number of people without increasing costs and we have, therefore, been concentrating on study days for patients and professionals and nationally based staff are undertaking vastly increased travelling around the country to Colleges of Further Education and local Associations taking with parents, young people and professionals.

Problems are so increasingly complex that we have also had to develop our in-service training programme, particularly for field workers.

Members of national staff presented papers at medical conferences including the Research Society meeting. This last paper was the result of a preliminary study of specialist services available in England and Wales for people with spina bifida and hydrocephalus. It provoked a great deal of discussion and has directed our attention to the importance of trying to improve these services.

An appropriate publication for this year has been 'Making Our Way' which describes the efforts and achievements of a group of young people.

Economic climate hits ASBAH too

THE FINANCIAL REPORT for the year was presented by the Honorary Treasurer, Mr R H Smith.

DONATIONS during the last year were £200,000 which was about the same as previously. Promotions were up, but legacies were down, and income from investments was much lower than in the previous year – £27,557 (1983: £45,609) because of the Association's smaller cash reserve.

Income was down by 1.5% over the year, whereas expenditure was up by 11.5%. A small comfort was that expenditure was 80% below the budget figure.

The deficit for the year was increased to £118,000 (1983: £46,248). This has had the effect of reducing the Working Capital to £243,538 from £362,049.

Serious though the deficit was it didn't come as a surprise. Unfortunately ASBAH was unable to increase its successful telesales operation as quickly as it wished because of the delay by several months in its move to the larger premises at 22 Upper Woburn Place. The move was now complete and the space selling department would be increased.

Whilst the Executive Committee would be reluctant to cut the services provided by the Association, this aspect would be examined very carefully from time to time. Much remained for ASBAH to do particularly with regard to accommodation for young people.

Unfortunately until general economic recovery it was difficult to see how the Association's financial position would be eased. There was a need for strenuous efforts to save.

The budgeted deficit for the coming year was £30,000.

THE THREE guest speakers at the Annual Meeting looked at the Chronically Sick and Disabled Persons Act 1970, from their own particular viewpoint. They were Sir Hugh Rossi MP, Mr John Gamble, a Director of Social Services, and Miss Judith Holman, a social worker.

The Act . . . as viewed by the former Minister

SIR HUGH ROSSI, MP, is a former Minister for the Disabled. He has maintained an active interest in matters concerning disabled people, and is a strong supporter of PHAB.

SIR HUGH began with a compliment. "You started your work in 1966, the same year I entered Parliament. And in that time, I have no doubt that you have achieved more and brought the greater happiness to the greater number . . ."

Sir Hugh then turned his attention to the Chronically Sick and Disabled Persons Act.

"I spent two years responsible for its operation and I have to say that I did not find it a very satisfactory piece of legislation. A law to be effective must be clear, precise and enforceable. The Act is none of these . . ."

"What it has done is to create a climate in which local authorities understand that they have a

Continued over page

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responsibility towards the disabled people in their area and in consequence they do things that otherwise would not be done.

"During my two years as Minister between 1981/2 and 1982/3 local authorities spent: £14 million in providing aids; over 9 million on adaptations; nearly £11 million in providing 106,000 telephone; over £11 million in providing nearly 130,000 holidays. I am sure that nothing like that would have been done by local authorities if the Act was not there to impose a general legal obligation, and to concentrate the mind.

"However, during those two years there was a continual undercurrent of complaint that the local authorities were not doing what they should be doing. Unfortunately the Act makes no provision for resources or takes account of other priorities. It is in effect a total open ended commitment for local authorities without any corresponding financial provision other than the rating system.

"The consequence seemed to be that some local authorities were trying to dodge their duties under the Act, and weren't doing what the disabled thought they should be doing.

"RADAR mounted a campaign with 14 other voluntary organisations, including ASBAH, in 1981. That campaign coincided with my arrival at the DHSS, and was sustained the whole time I was there. It was dropped shortly after I left – but I do not take this personally!

"RADAR looked at many hundreds of cases involving local authorities in England and Wales. Just 13 were referred to the Secretary of State for direction and fell on my desk".

Sir Hugh explained that under the National Assistance Act 1948 if, after an enquiry, the Secretary of State was satisfied that a local authority had broken a statutory duty, he could direct it to remedy this.

"In fact, no directions have ever been made in respect of the 1970 Act . . .

"I was determined to make a direction against a local authority if only to encourage the others, but no suitable case came forward.

"The reason lies in the weakness of the Act. It is worded in such a way that a direction can only be made in *individual* cases. So if a local authority says it is not going to provide holidays for disabled people, there is nothing the Secretary of State can do about it. But if a local authority decides a particular disabled person needs a holiday, and then doesn't provide it, then the Secretary of State could direct the local authority to provide it. I found this situation very frustrating.

"The only possible case in which the Secretary of State could insist is if there is an unlawful waiting list made up of a number of individual cases. Then it is possible to say that a direction will be considered for each individual case on the list. This I did as regards Liverpool where it had a telephone waiting list. This had the effect of moving the list fairly rapidly.

"It is the duty of the local authority to assess needs and then to make arrangements to meet these needs.

If the local authority decides there is no need, then the Secretary of State can do nothing. It is totally at the discretion of the local authority and there is no appeal against the decision. It is perfectly obvious that if a local authority wishes to drag its feet all it has to do is to be very slow in finding a need for individual cases.

"RADAR did prepare a Code of Practice to Standardise assessment and this was launched in July 1983, after I left office. I think this is still being discussed with a joint working party with the Local Authority Associations.

"I feel that amending legislation should be brought in to give a Right of Appeal to Tribunal or the Courts, not to the Secretary of State.

"In practice in order to avoid conflict the situation is sorted out by central government officials and the local authority and there is no need for ministerial direction. This is part of the reason why there has been no directions".

The Act . . . as seen by the Director of Social Services

JOHN GAMBLE is a Director of Social Services for South Glamorgan (Sir De Morgannwg). He is also President of the Council of the National Children's Bureau. Mr Gamble took the place of Mr John Jillings, President of the Association of Directors of Social Services who was unable to attend because of pressure of work.

MR GAMBLE began on a note of agreement. "I agree with Sir Hugh about the vagueness and lack of teeth of the Act".

He continued: "On the positive side the initial impact was to make the public aware of the needs of disable people and of how they can be helped in the community. For example Sections 4-7 of the Act relates to premises open to the public. Under these Sections a great deal has been done to help disabled people by means of access to, and facilities at, these premises. Furthermore handicapped people are now more involved individually on various Advisory Committees which come under Sections 9-16 of the Act.

"In more general terms the Act gave impetus to providing help and support by first of all identifying disabled people. However, the development of services has been to say the least very patchy across the country, not least because of the increasing financial constraints placed on Local Authorities and of the different priorities they have".

Mr Gamble referred to the need for an inter-

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disciplinary approach between the various local authority departments and voluntary bodies in order to provide continuity of care and to build up a proper understanding of the wishes of the individual disabled person, and the relationships within his or her family.

"It is not easy, but it is a challenge for the future, and will require all concerned to change attitudes and be prepared to 'share' expertise and resources much more 'openly' than has happened in the past. This together with the much closer involvement of disabled people themselves can only make for an improvement in the support we give and would certainly be more cost effective and in the spirit of the Chronically Sick and Disabled Persons Act".

Mr Gamble concluded: "I would like to mention that I was very excited to attend a 'send off' on a project called Operation Sahara Safari from South Glamorgan, when 10 handicapped people set off to travel approximately 7,000 miles in two minibuses to North Africa and back. Two of these handicapped people suffer from Spina Bifida. This is a most exciting and adventurous project and will show how handicapped people can cope in the same way as normal people, although I hasten to add that they would have appropriate medical, nursing and social support.

The Act . . . as experienced by the Social Worker

MISS JUDITH HOLMAN is a Social Worker in Chorley and a former member of the LIFT Committee. Miss Holman spoke from 'first-hand experience' because she herself has spina bifida.

MISS HOLMAN set about presenting a wider view. She said that she would not just talk about the Act but would look at it within the context of achievements made over the last 18-20 years. It was difficult to assess developments given the current economic climate and the varying reaction of local authorities to the Act. However, several general comments needed to be made.

She continued: "In the field of education, which is vitally important, there are several hopeful signs. People are beginning to realise that disabled children need more than just caretaking, they need a proper education. This is beginning to happen.

"Many children could go to 'ordinary' schools and there is the beginning of a move in that direction. The value of integration in the educational system is immense not just for the handicapped child but also for the 'ordinary' child as it provides the opportunity for the child to realise that someone who is handicapped is just like them really.

Handicapped people have got to fit in to 'ordinary' society at some time in their lives and integration into

'ordinary' schools is the best way of achieving this. ASBAH independence training programme is playing an important part in helping to introduce handicapped children into 'ordinary' schools by helping them to acquire the skills to fit in.

"Transport and mobility are also vital as they open the door to a full life, without them this is not possible, people are imprisoned having to rely on friends and family if they want to go anywhere, and so integration is not possible. Developments in motability and public transport are a great help. The ability to drive an adapted car as opposed to an invalid car has many benefits.

"Housing is also an important area if independence is to be achieved. One important criticism is that most accommodation for disabled people consists of single flats. Again, it is not the case that disabled people want to live alone. They, like anybody else might welcome the opportunity of flat-sharing.

"Long term residential homes are improving. There has existed an attitude within these homes that the staff allow disabled residents certain privileges, such as choosing their own colour schemes for their own rooms. Residential centres need to realise that for people who are in long term residential centres, this is their home and they should have the right to make decisions regarding their own home. This should not be seen as a privilege".

Access to buildings, particularly to new buildings, has improved greatly over the years said Miss Holman. There were notable exceptions, cinemas for example were rarely fully accessible.

Miss Holman stressed that it was important that planners realised that access to buildings did not just mean access for wheelchairs. It also meant access for people who walked with difficulty or had other problems. Their needs should be taken into account in the planning stages.

"There have also been improvements relating to employment. Job prospects are poor generally at the moment, and this increases the problems for disabled people who want to find employment. However, attitudes are now changing for the better and provisions for the disabled have improved", she said.

In conclusion Miss Holman said that she was cheered when reading ASBAH's Annual Report to see how ASBAH was constantly changing in order to respond to changing needs. This was particularly noticeable in the development of LIFT. It was also cheering to note that ASBAH recognises and responds to the need for co-operation with other organisations.

MR MICHAEL BOOTH, BA, ATI, retired from the Executive Committee and did not stand for re-election at the Annual Meeting, because of many other commitments. He was warmly thanked for his work on the Committee.

Mr Brian Henley was elected to the Executive. The Lady Jean Mackenzie, Mr R H Smith, Mr A Twyford, Mr T Robinson, Miss F Seward, MBE, BA, Dr A V Stokes, OBE, PhD, BSc, were re-elected to the Executive.

Horses can be the key to developing potential

How the Fortune Centre discovered the new Dawn

ONE OF Dawn Coleman's most prized possessions is a portrait of a large black gelding called Prince, by Jane Ramster who is well-known for her paintings of horses.

It was presented to 18-year-old Dawn recently for her conscientiousness, and co-operation with staff and other students at the Fortune Centre in the New Forest.

Two years ago when Dawn first left home — in Hastings, Sussex — and started as a student at the Centre her attitude to life was quite different. She lacked confidence and was generally unsure and indifferent to what the future might hold for her.

Dawn has spina bifida, but is not severely disabled. Nevertheless, about the only thing in life that had given her pleasure or a spark of enthusiasm was riding, and with the help of ASBAH's Field Worker, Mrs Gwen Wilkinson, Dawn was introduced to and accepted at the Fortune Centre in 1982.

At present it's the only centre of its kind — a residential rehabilitation and further education establishment for lesser handicapped and disturbed young people where the aim is to use horses as the motivation and incentive to develop whatever potential the students may have for their future lives. They do not all necessarily train for a career with horses.

Dawn, however, is one of the ones who is pretty sure that she does want to continue to work with horses. For this reason and because she has shown such aptitude, Dawn is staying on at the Fortune Centre to train as a Riding Therapist — just one of twelve riding therapy students there.

Riding Therapy is a new qualification introduced by the Fortune Centre and if after three years, Dawn is successful in gaining the Diploma, she will be one of only a handful of qualified riding therapists in the country. She hopes to be able to work at a stables where handicapped youngsters regularly ride.

An important part of the riding therapy training is appreciating learning problems. Dawn has already discovered that she enjoys working with impaired youngsters through helping the members of the local Riding for the Disabled groups who go to the Fortune Centre for lessons each week.

The main centre is purpose-built and set in the New Forest between Burley and Bransgore, a few miles from Christchurch. The other section is at Wootton Hall, five miles away, where most of the students and staff are housed in bright, attractive accommodation converted from old farm buildings. Dawn used to live there but has now moved to a bungalow at the main Centre along with the other first year therapy students. She has also changed trousers — from the beige jodhpurs of the ordinary students, to the navy breeches worn by the therapy trainees!

The Centre maintains a stable of horses and ponies



Dawn pictured at the Summer prize giving with the portrait of Prince.

who have been hand-picked for the different jobs they do. It also has at its disposal a small stud of New Forest ponies where students learn the aspects of work involved in breeding, breaking and training.

There are about 30 students on the basic courses — Further Social Education through Horsemastership Training for Employment & Rehabilitation — at any one time. By being responsible for a particular horse, earning his love and trust, being warmed by his acceptance and affection, the young people have found that they begin to build up a new image of themselves. They begin to realise that they are important and are needed, and this feeling is heightened when they get down to working with the disabled youngsters who come in for lessons — youngsters who are much worse off than themselves.

The students not only learn how to ride, but also gain experience of stable management, theory, different physical activities, sports, and basic living skills such as cooking, mending, etc. Some of them follow academic studies too — horse based, of course — leading to CSE's in English, maths, rural and environmental studies and religious knowledge.

That the courses have proved successful is shown by the fact that practically all the students have gone on from the Fortune Centre to further education of one kind or another, or found employment. About a third of the students are boys — a partial reflection of the general female predominance in riding in this country.

Referrals to the Centre come from a variety of sources — social workers, doctors, careers officers, teachers, but 40% have been introduced by Riding for the Disabled groups.

Dawn was a member of an RDA group in Battle, Sussex, and through them and with the help of ASBAH, she was referred to Fortune. Dawn was one of the lucky ones. There is a long waiting list, and a demand for the opening of similar centres in other parts of the country and abroad — notably in Australia and Canada.

All this has come about since 1977 although the Centre was not officially opened by Princess Anne until 1980.

Fees are paid by the social services, local education authorities, or MSC's special section for disabled people.



An aerial view of the Fortune Centre in the New Forest.

The two 'key' figures in the setting up of this Centre were the Hon Mrs Peter Baillie, the Executive Chairman, involved for many years with the Pony Club

and the ex-President of the New Forest Pony and Cattle Breeders' Association, and Mrs Yvonne Nelson, the Director, and a former chief riding instructor of Porlock Vale Equitation Centre who had also run her own schools both in the Midlands and in Canada where she first realised the impact of horses on slow learning and disturbed youngsters.

One of the Trustees and a member of the Executive is the Lady Jean Mackenzie, known to so many ASBAH members. Miss Moyna Gilbertson, ASBAH's Executive Director is on the Advisory Council of the Fortune Centre.

Why 'Fortune'? This was the happy name of a pony who 'taught' Mrs Baillie's children to ride and then went on to be used by children of the Brockenhurst Riding for the Disabled Group.

The purpose of the Centre — to restore confidence through achievement — is being fulfilled each year as students like Dawn start to take a real interest in life and to feel that they do have a niche, and are needed.

Cover Photo: *Story behind the picture*

THE HAPPY family pictured on the cover of this issue are Adrian and Ina Smith and their two children, Linn Annette, aged 2¼ years, and four-year-old Ann-Karin.

When Ann-Karin was born in Harrogate General Hospital in 1980, no one would have believed that today's happy picture would be possible, because she had spina bifida and hydrocephalus.

"Due to the severity of her condition it was decided to let nature take its course rather than to operate", writes Mrs Janet Smith, her grandmother who lives at Huby, near Harrogate.

When Ann-Karin was only two-months-old, Adrian and his Norwegian wife Ina, took her to settle in Norway. Adrian had to attend an adaptation course for three months before being allowed to practise as a vet and Ina decided to go back to nursing. The baby went into a home for brain-damaged children, the only one available.

Mrs Smith continues the story: "After six months, Ina felt that she could have Ann-Karin home. Each day she was collected by taxi and taken, from 9am-3pm, to a kindergarten for children with spina bifida and cerebral palsy. The staff were wonderful and did everything possible to help her. It soon became clear that Ann-Karin was a very strong child with a delightful personality and the kindest thing seemed to be to operate on her back to make movement much more comfortable."

"On a visit to England Adrian and Ina consulted with the doctors who had examined her originally, to see if it were possible.

"They agreed with the opinion of the Norwegian doctors and in September 1981 Ann-Karin was operated on for her shunt and in November for the closing of the back. The operations were a total success and she has gone from strength to strength. She has had two operations to straighten her feet and can now walk with the aid of calipers and a frame.

"She has recently entered a kindergarten for able-bodied children with her younger sister, now aged 2¼

years. She does get urinary infections but otherwise is a healthy child. She appears to enjoy life very much.

"We feel we are indeed blessed to have her as our eldest grandchild."

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MOTOR RACING, golf, parachuting – just three of the sporting ways in which ASBAH is currently raising money.

FRIDAY, September 28 saw the Association's first sortie into the world of motor sport when Richard Poole ran Full Throttle at Thruxton. Many stars of the music industry turned out, anxious for the opportunity to drive Formula 3 racing cars around the world famous track, having first fulfilled the qualification of finding £250 sponsorship.

Those taking part included Warren Cann of Ultravox, singer Nick Hayward and manager of Pink Floyd, Steve O'Rourke and BBC Radio One's Peter Powell was there to present live coverage as were TV South and Solent Radio. In addition to raising much needed funds, the event created a great deal of publicity for ASBAH.

CELEBRITIES also turned out on October 1 in order to join teams of three, sponsored by commerce, for a round of golf at Kingswood, Surrey, in the Kenneth Wolstenholme Golf Tournament. The day was rounded off by a supper at the 19th hole, when prizes were awarded to the winning players. This event was organised by Douglas Jack who managed to fit it in whilst pursuing his usual work of raising funds from trusts and industry, in which area he meets with considerable success.

CONTINUING the sporting motif, 17 policemen and 2 policewomen from Kentish Town Station all successfully completed basic training and first parachute descents at the Peterborough Parachute Centre on September 20 and 21. Despite the size of the group, not so much as a single twisted ankle was sustained by any of the jumpers, who now describe themselves as the Metropolitan Police Airborne Division! Sponsorship for the event is expected to be in the region of £3,000.

ON A MORE formal note at the time of writing, we at ASBAH are looking forward in eager anticipation to the Opera Ball, Scheduled to take place at



Triumphant members of the Kentish Town police force demonstrate a "grounded" stable fall position, having just completed their first parachute descents.

From great moments of sport, to the Opera Ball and on again to the Biggest Office Party of them all

Claridge's on October 9. Once again we are to be honoured by the presence of our Patron, Her Royal Highness The Duchess of Gloucester. The evening will feature an entertainment by members of the English National Opera and it is hoped that a substantial sum of money will be raised on the night by means of a computer auction.

This idea has emanated from the U.S.A. and marks the first time that such a fundraising ploy will be utilised in the United Kingdom. With such social events, as is usual, the greatest proportion of funds are raised by means of the sale of advertising space in the souvenir brochure and on this occasion our telephone sales department has excelled itself in producing a truly substantial publication the gross value of which to ASBAH should be in the region of £25,000.

CHRISTMAS is of course a traditional time for giving to charities and in addition to our usual direct mail activities, we shall also be seeking to maximise on the potential of the season of goodwill by staging the Biggest Office Party in London at the Hammersmith Palais on December 10. Tickets for this, at an advance booking price of £3 (£4 on the door), are available from our offices and it would be nice to hear from LINK readers as I know that we can promise a truly memorable evening, featuring no fewer than three bands and a variety of other amusements in line with the Christmas party theme!!

There is a further reduction for office blocks (sorry!) so why don't you treat yourself and your colleagues to a special night out for our favourite charity!

AS 1984 draws to a close we at ASBAH feel that George Orwell did indeed miscalculate for it has been a year of unparalleled generosity to our Association, although inevitably the supply of money can never equal the demands of those for whom we care. Nevertheless, so very much more is being achieved as each year passes and it is therefore appropriate to say a big thank you to all our supporters but especially to you, the readers of LINK, for all your interest and help, during the past year.

JUDY KAY
Appeals Director

CLASSIFIED 'ADS'

The advertisement rate is:
£2.25 for up to 30 words. £3.30 for 30-45 words.
£4.50 for 45-60 words.

Please send remittance with your advert.

Please note that there is a 10% discount if you book six advertisements in advance.

Adverts for the next LINK (Jan/Feb) should be in by December 5. Send to the Editor Mrs Susan Gearing at home: The Gables, Long Lane, Wrington, Avon. Tel: Wrington 862279.

HOLIDAY ACCOMMODATION

MOLD, Heart of Clwyd. Two luxury self-catering bungalows, fully adapted for wheelchair bound owner. Sleep 4/6. Set among magnificent pines in heart of Clwyd, yet 20 minutes from North Wales coast. South facing private gardens. Central heating. £85-£135 per week; Discounts for disabled families. Brochure: Mrs Lynne Dowling, 23 Gleneagles Road, Great Sutton, South Wirral L66 4NF. Tel 051-339 5316 or 051-355 1005.

HEYSHAM, Nr. Morecambe. Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 5 Roman Way, Whitchurch, Shropshire. Tel: Whitchurch 3691.

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.

ASBAH Publications

Children with Spina Bifida at School
 Ed. P. Henderson, CB, MD, DPH.....70p
The Handwriting of Spina Bifida Children
 Joan Cambridge and Elizabeth M. Anderson.....£1.60p
Sex for young people with spina bifida or cerebral palsy£1.75p
The Nursery Years
 Simon Haskell and Margaret Paull60p
Little Joe (A Grandmother's story)
 Winifred Foster.....40p
Life and Death — thoughts on bereavement75p
Making our Way — individual experiences of young people with spina bifida and hydrocephalus£1.20p

All the above prices are inclusive of postage and packing.

Information leaflets.....100 for £4
 Fact sheets — (on a wide variety of subjects)up to 10 copies free
 Asian language translations of a Fact Sheet about spina bifida and hydrocephalus and ASBAH's work are available free (up to 10 copies) from national office. Translations are into Bengali, Gujarati, Hindu, Punjabi and Urdu.
 Welsh language sheets are also available — up to 10 copies free

Please send at least 30p postage.

EXCHANGE & MART

Leisure Wear: White cotton Tee Shirts with green family symbol and words 'Support Spina Bifida'. Also Sweat Shirts in reverse colours. All sizes. Details from Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

Ortho Kinetic Chair for sale. £100 or offers. Please apply to: The Secretary, KASBAH, 4 Scott Lose, Ditton, Maidstone, Kent.

BEC 40 Horizon electric wheelchair for sale. Hardly used. Centre mounted kerb climbing device. Failsafe dynamic brake motor. Fits into average family car. £900. Details: Mrs M. Olloman, 5 Liddel Close, off Solway Road South, Luton, Beds. LU3 1TW.

LOCAL ASSOCIATION SECRETARIES

The following changes have taken place since the last LINK.

A full Directory will appear on the back of the next issue:

Bedford & District Hayes, Middx.
 Mr I. Pickering, UB3 4NY.
 Haylands, Tel: 01-573 5488.
 41 Box End Rd,
 Bedford.

Tel: Bedford 0234.

Kent
 Mrs Cynthia Capon,
 4 Scott Close,
 Ditton,
 Maidstone,
 Kent.
 Tel: 0732 844953.

Hillingdon
 Mrs B. Brannen,
 30 Fairey Avenue,

St Helens & District
 Mrs N. Maddocks,
 236 Rainhill Road,
 Prescot,
 Merseyside L35 4LD.
 Tel: 051-426 3921.

Suffolk
 Mr D. J. Lawrence,
 69 Woodberry Way,
 Walton on the Naze,
 Essex CO14 8EW.
 Tel: Frinton 5245.

JOHN GROOMS HOLIDAYS

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

Seaside Hotels: Llandudno and Minehead. (Bargain Winter Breaks for only £10 per day, incl. VAT)

Self-Catering Units: Near the sea at Barnstaple, Borth, Poole, New Milton, Tenby, Looe, Maplethorpe and Camber Sands. Also in the Cotswolds. Ramps and other aids

Holiday Chalet: Near Skegness (Lincs)
 London Holiday Flat: London, N.4.

Motor Caravan: Hire for one or two weeks. Tail lift, wheelchair, WC/Shower unit, etc.

Bungalow: In the heart of the Norfolk Broads

Canal Holiday: In adapted narrow boat.

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

A new benefit for some long-term sick and disabled people.

From November 29th 1984 some long-term sick and disabled people will be able to claim a new benefit if they are unable to work and don't qualify for Sickness or Invalidity Benefit.

The new benefit is called Severe Disablement Allowance (SDA for short), and will be worth £21.50 a week, tax free. It does not depend on National Insurance contributions, and doesn't involve a means test.

SDA replaces Non-Contributory Invalidity Pension (NCIP) and Housewives' Non-Contributory Invalidity Pension (HNCIP).

Everyone who already gets NCIP or HNCIP will be transferred to SDA automatically in November 1984.

The main difference between SDA and the present benefits is that married

women will be able to claim SDA even if they are able to carry out normal household duties.

People who have been incapable of work since before their 20th birthday can qualify for SDA simply on that basis. Those who become incapable of work later in life must also be severely disabled to qualify.

People aged 50 or over and those aged 16 to 34 can get SDA from November 1984.

Those aged 35 to 49 cannot get SDA until November 1985, but should claim NCIP or HNCIP before 29th November if they are eligible.

To find out more just send the coupon to: DHSS Leaflets Unit, P.O. Box 21, Stanmore, Middlesex HA7 1AY.

Please send me the explanatory leaflet and claim form for:
Severe Disablement Allowance NCIP HNCIP Tick the one(s) you want.
(Please allow 21 days for delivery.)

Name _____

Address _____

L2 Postcode _____

Issued by the Department of Health and Social Security.