Link

FEBRUARY 1992 NO 138
Price 30 pence

The magazine for people with
Spina Bifida and/or Hydrocephalus

IN THIS ISSUE

NEW BENEFITS FOR '92

ASBAH ADVISER WINS AWARD

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

LOOK INTO THE FUTURE TODAY

LIFT

The magazine for young ASBAH readers

February issue out NOW

Features:

- ★ LIFT research results
- ★ Careers advice
- ★ New Benefits explained

Contact Lynn at National Office to get your FREE copy

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Link

FEBRUARY 1992
ISSUE NO 138

CONTENTS

- Update 4
- New Benefits for '92 8
- Continence Services 10
- Award for Adviser 10
- Bladder Management 12
- Out & About 14
- Research 16
- Letters 16
- Technology 18
- Ads 19

The magazine for people with spina bifida and/or hydrocephalus

Editor: Gill Winfield

Published by **ASBAH**,
ASBAH House,
42 Park Road,
Peterborough PE1 2UQ
Telephone: 0733 555988.

LINK SUBSCRIPTION 6 EDITIONS – 12 MONTHS

UK £3.30

Europe and Overseas Surface Mail .. £5.60

Air Mail £12.50

All payments should be made in Sterling.

Registered charity no. 249338.

An appeal to our Local Associations for a cash injection, to help maintain the momentum of two important pieces of ASBAH-funded research, has produced a magnificent response, with £5,500 being donated.

The work - one study dealing with the health and social needs of young people, the other with their sexuality - is being carried out by Dr Martin Bax, chairman of our Medical Advisory Committee, and ASBAH's research fellow Maddie Blackburn.

The costs had risen since the studies were agreed, but National ASBAH was unable to fund the difference from its own resources.

"We had a marvellous response. Local Associations obviously shared our view that the work is of major importance, and were as keen as we are to see the results," said executive director Andrew Russell.

This research has now been given a massive further boost through the generosity of Midland Association, who have given an extra £5,000 - part of the proceeds of a charity benefit concert, played by the rock group Status Quo at the NEC, Birmingham, in September.

This money will be used to help fund Maddie Blackburn, the ASBAH research fellow, who is devoting her time to these two research studies and gave an update on the project in our last issue.

COVER – *Claire McKernan and Ruth Madoc who will feature in ASBAH's TV appeal, see page 4*

Keeping you informed

Details of another ASBAH-funded research project are given in this issue. In 'Looking at our image', on page 16, Dr Philip Minchom and Mr Peter Appleton tell us about their research into the self image of young people with spina bifida - the project is due for completion later this year.

Television appeal to the nation

A nationwide TV appeal for ASBAH will be broadcast on all ITV channels in England and Wales on Sunday, 16 February, at 6.40pm.

Actress Ruth Madoc, who became famous as Gladys Pugh in the long-running comedy series "Hi De Hi!", will introduce ASBAH and the McKernan family, who live on Barry Island, South Wales. Mr and Mrs McKernan have a nine-year-old daughter Claire, who has spina bifida.

Ruth Madoc, who lives near Peterborough, has already become closely associated with ASBAH's Fund-a-Fieldworker Campaign in Cambridgeshire.

She has met staff at National Office and received a cheque on our behalf for a charity evening at the local theatre.

A team of volunteers from National Office will man a 20-line telephone system to take credit card donations and pledges on 081 992 7766. The lines will be open from the end of the broadcast until 9pm.

The ITV charity appeal is being produced by a film crew from Bristol-based Harlech TV West, which handles all the network's charity appeals.

Below: Ruth Madoc meets the McKernans.

Early treatment of hydrocephalus

In the December issue of LINK we published "Hydrocephalus in Infancy - Recent advances in treatment", this was an article by Dr M Wearmouth of Basingstoke District Hospital describing her use of drugs in the early treatment of hydrocephalus in newborn babies, prior to shunt insertion. Unfortunately, Dr Wearmouth's byline was missing from the end of the article, our apologies for this omission.

Further Funds for KASBAH

Kent ASBAH is well over £500 better off (rather than £50 as printed in the last issue of LINK) following a 120-mile cycle ride by Mr Derek Boosey. And at the time of going to print the proceeds from sponsorship had grown even further, to £695.50.

The man from Barclays

A new member of staff joined ASBAH's finance department, in December, at absolutely no cost to the Association.

Colin York has come in to assist finance director Derek Knightbridge on a three-year secondment from Barclays Bank. He was an operations manager at the bank's branch in Church Street, Peterborough.

Our thanks to Barclays, whose generosity will make it possible for Mr Knightbridge to devote more time to strategic direction and less on administration.

ASBAH's Counselling Service

For financial reasons ASBAH will cease to provide a Counselling Service through a national team of counsellors from the end of this financial year - 31 March 1992. The posts of Accommodation Adviser and Conference Organiser will also go as part of ASBAH's essential cost-cutting measures.

Executive Director Andrew Russell announced the redundancies: "The loss of these posts is a very unfortunate consequence of the economic recession, which has forced the Finance and General Purposes Committee of our Executive to consider carefully how cuts can be made in expenditure. All ASBAH's posts and activities have been reviewed in reaching these decisions. Naturally, the redundancies will cause consternation amongst members and staff but I believe that, following this retrenchment, we can build positively on our services as the recession lifts."

Fieldworkers and other ASBAH staff who are currently in post will, of course, continue to respond to requests for advice and support.

Co-op customers provide handsome dividend for ASBAH

CHEQUES totalling over £9,000 have been presented to the Association, thanks to a charity number which customers of the Co-op can quote, instead of their own share number, when making purchases.

Share number 600 has raised more than £18,000 this year and the Anglia Regional Co-operative Society is dividing the proceeds between ASBAH and the Children's Haven Fund.

And that's not the end of the story, as a Society spokesman told LINK: "The £9,000 are interim payments from our charity 600 share number, covering the period from February to August 1991. We have still to hand over the money received between August and January 1992". So ASBAH can look forward to another 'dividend' later in the year.

ASBAH's share of the dividend has been made-up from five stores within the region:

Greater Peterborough region - £5,400 - Westgate store, Peterborough - presented by Mr Alec Arlow, President of the Society; South Lincolnshire region - £700 - at Stamford - Mr Neil Double, Vice-Chairman; West Norfolk region - £1,100 - King's Lynn - Mr Melvyn Hill, Chief Executive; Ouse Valley region - £700 - St Neots - Mr Hill; Waveney region - £1,100 - Lowestoft - Mr Cresswell Knights, Chairman of the Board of Directors of Waveney region.

Right:Andrew Russell and Rachel Stanworth hold up the ASBAH cheque, presented by Alec Arlow. Photo courtesy of Peterborough Evening Telegraph.

Would you come to a study day?

Following our recent features on bowel management and the personal account of continence problems by an ASBAH member, our Continence Advisory Service has received many phone enquiries from readers.

For this reason, our continence advisers feel it might be appropriate to hold a study day on bowel management for people with spina bifida. But as this can be a rather sensitive topic we would first like to know whether such a study day would attract sufficient participants.

If you would be interested in attending a bowel management study day, please write to Jane Williams at ASBAH House, 42 Park Road, Peterborough PE1 2UQ . Jane would also like to know if there are any particular points you would like to see discussed at the study day.

Statements stream in

When ASBAH's education adviser, Peter Walker, offered to go through draft Statements of Special Educational Needs, in our Hydrocephalus Support Group newsletter, little did he realise what a splendid response he would get.

If there are parents who need help urgently, with their child's Statement, they should telephone Peter at National Office. If you need to send Peter a draft statement and Local Authority assessments, you should be prepared for some delay in receiving a full response. Peter Walker works part-time and also spends some of that time on work outside the office.

Office Move

ASBAH's Eastern Region Office has been renamed ASBAH South East Regional Office and will be run from Ground Floor, 26 Coniston Road, Muswell Hill, London N10 2BP by the regional co-ordinator, Gina Broughton. Telephone 081 883 6387.

ASSOCIATION FOR SPINA BIFIDA AND HYDROCEPHALUS

Executive Director:
Mr Andrew Russell,MA

Finance Director:
Mr Derek Knightbridge, FCCA

Assistant Director (Administration):
Mr Paul Dobson, BA, (Hons), MIPM

Fieldwork Manager:
Mrs Teresa Cole, MICA

Disabled Living Service Manager:
Miss Rachel Stanworth,BA (hons), SRN, PGCE, MSc

Publicity Manager:
Mr Tony Britton

Research and Information Officer:
Miss Pat Corns, SRN

Five Oaks Centre Manager:
Miss Joan Pheasant, NCC

Appeals Manager:
Mr Roy Johnston

Call for care changes rejected

The Government has rejected a call for a major rethink on local authority charges for home care services, despite pressure from a consortium of disability organisations, which included ASBAH.

In an open letter to Health Secretary William Waldegrave, the consortium had expressed grave concern about the growing trend of local authorities to charge disabled people for home care services - as much as £10 an hour for domestic assistance. Particular concern was voiced about services which are being taken over by local authorities under the 1990 NHS and Community Care Act. This led to people being asked to pay for services which used to be delivered free, via NHS staff.

As a member of the consortium of 18 organisations, ASBAH had especially expressed concern about charges being higher when clients were in receipt of Attendance Allowance and the fact that there were variations in costs throughout the UK. Our suggestions were that Attendance Allowance should be disregarded when means testing takes place - as is the case in Income Support claims. We also commented that ability to pay should not bar people from receiving the care that they need.

In a reply to the consortium's letter, from Virginia Bottomley, Mrs Bottomley argues that it is reasonable for authorities to charge where the service includes personal care.

The consortium is urging the Government to think again on this issue and believes that disabled people should not have to pay for the privilege of receiving personal care services - such as help to get dressed, or use the toilet.

If you feel you are being unfairly charged for such basic services, write to your local MP and bring this situation to his attention.

EDUCATION CAMPAIGN

Skill -the National Bureau for Students with Disabilities - has produced a Campaign Pack relating to the Further and Higher Education Bill which is currently going through Parliament. They want the interests of disabled students to be acknowledged in the legislation and the pack shows how you can make your voice heard. Packs cost £1.50 from Skill at 336 Brixton Road, London SW9 7AA, tel: 071 274 0565.

Justice for SDP claimants

A lobby of Parliament to demand justice for Severe Disability Premium (SDP) claimants is being called for by Derbyshire Carers Concern, with support from national organisations including RADAR and MENCAP.

The lobby is aimed at ensuring that severely disabled people are not denied SDP because they are living with someone else - many disabled sons and daughters in their 40s and 50s are excluded from SDP because they live with parents in their 60s and 70s. The premium is worth £32.55 per week from April 1992.

The lobby of Parliament is on Wednesday 18 March. There will be a meeting and rally in the Grand Committee Room, House of Commons at 11.30am with a lobby of individual MPs by their constituents at 1.30pm.

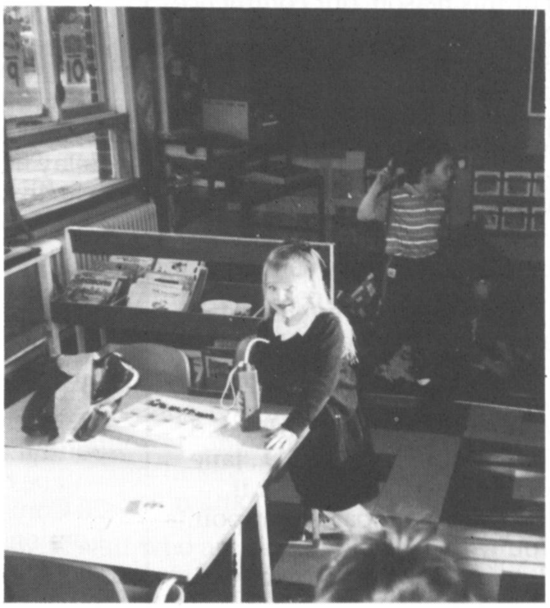
Further information can be obtained from: Derbyshire Carers Concern, Long Close, Ripley DE5 3HY, telephone 0773 746 101.

LET'S GET TOGETHER

National Integration Week is a special event being organised by the Centre for Studies on Integration in Education (CSIE) who want to use the week (from 11-17 May) to demonstrate the benefits of integrated education all over the country.

CSIE are inviting voluntary organisations, local authorities, schools, colleges, Government departments and all interested parties to mark the week with suitable activities - from exhibitions and study days to plays - which celebrate integration. And they will publicise your activity in a special brochure, providing they have the details by 21 February.

If your group, school, or organisation wants to be involved or needs more information, contact CSIE at 415 Edgware Road, London NW2 6NB, telephone 081 452 8642.



Right: Integration in a Sheffield primary school for a young girl with spina bifida.

REAL LIFE RESCUE FOR TRAINEE LIFEGUARD

BRIAN WAUGH, a 19-year-old trainee lifeguard, was just on his way home from his shift at the swimming pool when he noticed a little girl in difficulty at the deep end of the teaching pool. "She was under the water and struggling to get back up for air," said Brian. "I was fully clothed as I was about to go home but I jumped in to get her out, before calling for assistance."

The three-year-old child was none the worse for her ordeal and Brian has been recommended for the Friends of Northumberland and Durham Life Saving Society certificate, in recognition of his quick-thinking action.

Brian, who has spina bifida, has been at Consett's Belle Vue swimming centre for a year on a YTS scheme and is hoping to go on to obtain his Teacher's Certificate in swimming, as part of his employment training at the centre.

He's no stranger to the water - having swum for England in the 1987 Disabled Games at Edinburgh where he won two golds and a silver - and hopes to make his career as a swimming teacher.

Do you need a sign?

A workshop for disabled people, which was originally set up by Midland ASBAH, specialises in making signs, engraving and badges.

In recent years the Spina Bifida and Hydrocephalus Workshop, in Birmingham, has been struggling to keep running, since their Inner City Partnership Grant was withdrawn. And last year they launched a £50,000 appeal in a bid to stay open. "We have had a very good response from local individuals and trust funds and our sales are increasing," said Mr Godfrey Chesshire, who is the workshop manager. But they still need to improve on their regular income to secure the future of this sheltered workplace for 20 young people. They are opening their fourth shop in the city shortly and have recently provided all the signs and badges for a new psychiatric hospital. But if you, or your group, need any badges, signs or engraving work doing, why not contact the workshop - you'll be supporting a good cause.

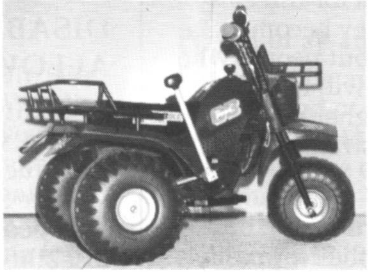
For further details on their work, or to make a donation, contact Mr Chesshire, 14 Court Road, Sparkhill, Birmingham B11 4LX, telephone 021 771 0380.

Product News

Fun bike

Stuart Dunne, designer, manufacturer and user of the Cyclone lightweight wheelchair, has teamed up with a toys importer in the North West to produce an electric mobility product for children with fun in mind. The Cat 2 is a battery powered vehicle which was designed originally for use by able bodied children. But when Gail Powell from Chester contacted the company to ask if such a bike could be converted, for her son Ian to hand operate, the answer was 'yes'. A simple conversion to hand operated controls for brake and accelerator was made.

The bike is designed for children aged between four and 10 years and has a load capacity of 40 kilos, speed of 3-5 kmh and continuous use of 3-4 hours per battery charge.



Adaptations made to the trike include hand operated 'throttle' for forward and reverse drive and hand operated brake unit.

The price of the bike is yet to be decided but will be around £200-£250. All enquiries to Stuart Dunne, CJS Custom, Unit W6, Chester Enterprise Centre, Hoole Bridge, Chester CH2 3NE, telephone 0244 310089.

Cushions by post

A lightweight, foam wheelchair cushion, for prevention of pressure sores, is available by post from Ultra Clean. The 'Pressure Guard' cushion has a patented air ducts profile, to allow free circulation of air and prevent moisture build-up. Sold complete with an inconti-guard cover and outer towelling cover, the cushions retail at £54.50 plus VAT. Bulk purchases, for sale by organisations to their members, are available at reduced cost.

For more details, contact Pressure-Guard Retail Sales, Ultra Clean, 244 Nantwich Road, Crewe, Cheshire CW2 6NS, telephone 0270 501571.

Products featured in Product News have not been tested by ASBAH.

NEW BENEFITS FOR '92

TWO NEW Social Security Benefits will be introduced in April 1992 for people who have a disability or a long-term illness - Mary Malcolm, Assistant Manager, Fieldwork, unravels the regulations.

DISABILITY LIVING ALLOWANCE (DLA)

This allowance is for people disabled before the age of 65, the present Mobility Allowance and Attendance Allowance will be brought together and extended into one benefit and called Disability Living Allowance (DLA). The amount a person gets will depend on how much help is needed with getting around and with personal care. For people disabled after 65, Attendance Allowance will continue as now, to help with personal care needs.

Disability Living Allowance will consist of two components - care component and mobility component.

Care component

The Care Component of DLA is for people who need help with personal care. There will be three rates depending on the amount of care a person needs:

- The higher rate will be paid if a person needs help both day and night.
- The middle rate will be paid if a person needs help either during the day or during the night.
- The lower rate will be paid if a person needs some help during some of the day (but less help than for middle rate), or if over age 16 would need help to prepare a cooked main meal.

People who are terminally ill will be able to qualify for the highest rate of the care component.

Mobility component

The other component of DLA, the mobility component, for people age five or over, will be payable at two rates:

The higher rate will be payable if a person:

cannot walk at all or

has had both legs amputated at or above the ankle or was born without legs or feet or

is both deaf and blind or

is severely mentally impaired with severe behavioural problems.

The lower rate will be payable if a person can walk but needs someone with them to make sure that they are safe, or to help them to find their way around.

Qualifying period

There will be a three month qualifying period for both components of DLA. Normally, a person has to satisfy the qualifying criteria for three months before they become entitled to DLA, but people who are terminally ill will be able to qualify for the higher rate of care component straight away.

Self assessment

DLA will rely on new methods of claiming with the emphasis placed on the disabled person's own assessment of the effect that their illness or disability has on their life. Decisions will be taken by independent Adjudication Officers.

Reviews

A person dissatisfied with an Adjudication Officer's decision will have the right to an informal review by a different Adjudication Officer.

New appeal rights

If a person remains unhappy following a review decision, they will have the right to appeal to a new independent Disability Appeal Tribunal. At least one member of the tribunal will be someone who is experienced in dealing with the needs of disabled people.

When to claim

Claims for DLA will be accepted from 3 February 1992 and payment will start from April 1992.

People over 65

DLA is for people whose disabilities start before age 65. Once awarded, DLA will continue to be paid, irrespective of age, providing their criteria continue to be met.

For people whose disabilities start after the age of 65, Attendance Allowance will continue to be available.

Existing MobA and AA beneficiaries

Existing Mobility Allowance and Attendance Allowance claimants will benefit under DLA as under the current arrangements, providing their circumstances remain unchanged. Attendance Allowance continues for those aged over 65.

DISABILITY WORKING ALLOWANCE

Disability Working Allowance (DWA), which will be introduced from April 1992, is a tax-free Social Security benefit to help people with an illness or disability who are starting work, or are already working.

Who can claim DWA

People aged 16 or over who satisfy all three of the following conditions may be able to get DWA.

WORK - DWA will be available to people who are starting work for 16 hours or more a week, or are already working 16 hours or more a week. This can be self-employed work or working for an employer. If the job is temporary it must be expected to last at least five weeks.

DISABILITY - DWA will be available to people who have an illness or disability which puts them at a disadvantage in getting a job. The definition of what constitutes a disability, which puts a claimant at a disadvantage, will be set out in regulations.

QUALIFYING BENEFITS - to qualify for DWA a person must:

- Have been getting - Invalidity Benefit (IVB), Severe Disablement Allowance (SDA), or a disability premium or higher pensioner premium paid with Income Support, Housing Benefit or Community Charge Benefit, in at least one of the 56 days before the date of claim, or
- Be getting - Attendance Allowance (AA) Mobility Allowance (MobA) or Disability Living Allowance (DLA) or have an invalid 'trike'.

How much

DWA will be an income related benefit . The amount of DWA will depend upon the make-up of the claimant's family and their financial resources such as income and capital, with a tapered withdrawal of benefit as incomes rise.

Capital

People with more than £16,000 will not be entitled to DWA. For people with capital between £3,000 and £16,000 a weekly income will be assumed and taken into account in the calculation of DWA. Some forms of capital will be ignored, such as the surrender value of a life insurance policy and occupational pension or an annuity, compensation from personal injury held in trust and the value of a person's home and their personal possessions.

Income

Income is all the money that is coming into the claimant's household, including earnings, other income and an assumed income from capital. Tax, national insurance contributions and half of any contributions to an occupational or personal pension will be deducted from the earnings which are taken into account. Disability Living Allowance (DLA) will be totally ignored as income in the calculation of DWA.

Disability

FOR FIRST CLAIMS - A simple declaration by the claimant that they have a physical or mental disability which puts them at a disadvantage in getting a job, will usually provide sufficient evidence of disability.

FOR SECOND and subsequent claims - Claimants will be given a list of functional disabilities which are likely to put them at a disadvantage in the labour market and will be asked to indicate which apply to them. To 'pass' the test they will have to have one or more of the specified disabilities. They will also be asked to name a professional involved in their care who can provide confirmation of their assessment. People who are receiving DLA at the higher rate, or who were getting SDA before claiming DWA, will be assumed to satisfy the disability test and will generally not need to complete a self assessment form.

Period of award

DWA will be awarded for a fixed period of 26 weeks, and will not alter to take account of changes in the claimant's circumstances. Eight weeks before the award ends the claimant will be sent a form on which to make a renewal claim - renewal claims can be made within the period six weeks before and two weeks after the end of the DWA award.

National Insurance (NI) credits

Class 1 NI credits will be awarded to DWA claimants whose earnings in any week fall below the lower earnings limit for paying NI contributions.

Reviews

All decisions about a claim will be taken by independent Adjudication Officers. A person dissatisfied with an Adjudication Officer's decision will have the right to an informal review by a different Adjudication Officer.

Appeals

If a person remains unhappy following a review decision they will have the right of appeal to a new independent Disability Appeal Tribunal. The tribunal will have at least one person who is experienced in the needs of disabled people.

Linking

A person receiving DWA who was receiving IVB or SDA before claiming DWA, and whose attempt at work fails within two years, and who is incapable of work, will be eligible for the benefit they were receiving rather than for Sickness Benefit. This "linking rule" is unique to DWA. The normal rule is that people who give up IVB or SDA can return to them only if they become incapable of work within eight weeks, otherwise they have to reserve a 28 week qualifying period.

When to claim

Claims for DWA will be accepted from 10 March 1992 and the first payments will be made on 14 April 1992. The benefit will be widely publicised ensuring that disabled people will know how and when to claim and where to get advice.

Further information and assistance with applications can be obtained from your local DSS Office or by ringing your DSS FREE Advice Line.

An Agenda for Action

IN THE SUMMER of 1991 ministers from the Department of Health called for a report into continence services throughout the country. It seemed, from recent evidence, that the service was patchy with problems in some areas on the quality and level of service offered. Judy Sanderson, from the Department of Health, undertook the investigation and ASBAH responded to her report in November.

In a letter from Baroness Hooper, Parliamentary Under Secretary of State for Health (Lords), ASBAH was thanked for its comments. Our views will be considered by the "Task Force" which is being set up within the Department of Health to take forward recommendations from the 'Agenda for Action'. Here we outline the findings of the report and ASBAH's comments on it.

REPORT FINDINGS

The report recognised that poor quality continence services seriously affect the quality of life for many people and can lead to social isolation and high stress rates in both those affected and their carers.

It was pointed out that 70 percent of the people with a continence problem can be cured (the report was not specific to incontinence caused by disability) and the other 30 percent can benefit enormously from proper management. This includes the full assessment of any need for pads. The Agenda recommends mounting a cost-effectiveness study to look at the true economic costs of incontinence and says that hard information is needed to confirm that money spent on continence services produces savings elsewhere in the health and social care system - by, for instance, preventing unnecessary admission to residential care.

The Agenda suggests a variety of ways in which professionals' education in continence skills could be improved: such as incorporating some form of continence training into the GP trainee scheme and ensuring that nurses receive high quality training at an early stage of their education.

The key features of a good service were identified by the report as

- Active, enthusiastic consultant and general manager involvement.
- Continence advisers with management and teaching skills and who carry a small patient caseload to keep their clinical skills up to scratch.
- The effective use of a computer to store, monitor and review patient

She's a winner

In the December issue we told readers that ASBAH continence adviser Mary White was in the running for a prestigious nursing scholarship - now we're delighted to be able to tell you that she was successful. Mary was awarded the Smith and Nephew Foundation/Florence Nightingale Scholarship, worth £4,000. It will enable her to travel in the USA and Canada, visiting centres of expertise in continence training and treatments.

Mary explains the work of ASBAH's continence advisers and why she was motivated to apply for the Scholarship.

"The continence advisory service was less than one year old and we were more convinced than ever that our project should not only survive, but flourish. We know that full continence in spina bifida is possible if training is started early and if training plans are drawn up in accordance with requirements of the family and the demands of the school day.

Financial restraints placed a limit on the amount of actual casework we could afford to carry and so we had to reassess our situation. The decision was made to concentrate the main thrust of our effort on training other professionals in health, education and social services who provide education and care for our children. These professionals are continually seeking guidance and advice from ASBAH and so we decided to provide training for parents and professionals whenever and wherever possible.

The presence of neuropathic bladder and bowel

on Continence Services

information.

- A sympathetic and knowledgeable person answering the phone.
- The public being aware of the service through active publicity work.
- A separate budget.

Other important features may emerge from the research work currently being undertaken by the Social Policy Research Unit at the University of York on the role of continence advisers.

The Agenda also commented on the social taboos which are still associated with the subject of incontinence. They reported that professionals are sometimes too embarrassed to ask the right sort of questions which could mean that the answer to a continence problem would be 'throwing a pad at it.'

The recommendations of the Agenda were accepted in full by Ministers and will be implemented in the course of two years.

Copies of the full report 'An Agenda for Action on Continence Services' can be obtained from the Health Publications Unit, Site No 2, Heyward Stores, Manchester Road, Heywood, Lancashire OL1O 2PZ.

ASBAH'S RESPONSE

ASBAH welcomed the Agenda and agrees with many of the findings but feels that it does not go far enough as it does not require the authorities to provide a minimum standard of service.

In particular the Association was disappointed that people with disabilities, especially children, were not mentioned in the report. If this group had been considered, it would have been necessary to emphasise the importance of urodynamic clinics and the surgery available. Inclusion of childhood incontinence would also have necessitated mention of the school nurse role.

With the integration of disabled children into mainstream schools, there are implications for the responsibility of continence/independence training of the child. At present there is no policy on this.

YOUR INPUT

Our continence advisory service is continuously reacting to developments in this field and keeping Government and health authorities informed of our clients' interests in the provision of continence services. We would like to hear from you of any problems you have with supplies or service, so that we can closely represent your case. Contact Jane Williams, ASBAH continence adviser, at National Office - address on page three.

---

renders the individual doubly incontinent and therefore dependent upon carers. It is possible, however, to teach young children to take responsibility for their own continence by working closely with hospital consultants, community health services, education and social services. The problem is a complex one requiring specialist knowledge. Paediatric surgeons and urologists feel more able to take positive action if they feel that there are the skills available in the community to teach and support the family, to liaise with schools and design daily programmes for independence and continence training.

Although the subject is broadly continence training, it is highly specialised because it is based upon the study of the medical and surgical aspects of the neuropathic bladder and bowel. It does, however, also encompass special needs in education (Statementing, behaviour, learning difficulties), community health services, social services, sexual awareness and counselling. This multi-professional commitment can only be requested after a broad and thorough assessment of the medical, social and educational needs of the child.

The choice of drugs, continence aids, surgical and medical options needs to be fully understood.

Much of my time is spent in training other professionals including doctors, nurses, teachers and social workers. Designing study days for other professionals is a valuable vehicle for promoting our ideal and it also enables us to 'earn our keep'.

In order to continue to provide a high standard of training for other professionals, it is vital that we have access to the latest developments in treatment and management and this would be an expensive burden for ASBAH to carry.

The Smith and Nephew Foundation/Florence Nightingale Scholarship is designed to enable the recipient to travel overseas to centres of expertise and therefore study the latest forms of treatment and research. It was a great pleasure to be selected for interview but the fact that the committee decided to award the scholarship to me is, I feel, indicative of the importance that they attach to our project and acknowledgement of the needs of our children.

I am looking forward to my six weeks travel during 1992 and intend to use the knowledge I will gain to improve the continence management of the children in our care."

BLADDER M

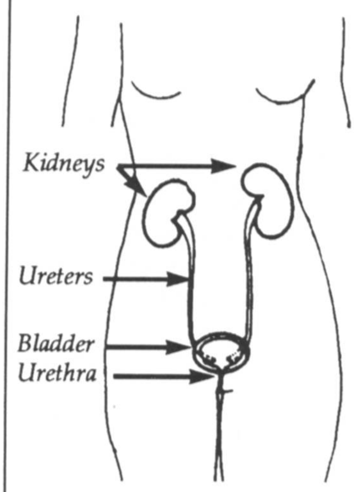
IN THE LAST ISSUE of Link we looked at how better bowel management might be achieved, now Mr Victor Boston, consultant paediatric surgeon and member of ASBAH's Medical Advisory Committee, explains some of the bladder problems associated with spina bifida and how these can be treated.

People born with spina bifida, with or without hydrocephalus, and regardless of whether or not they experience difficulties with mobility, will usually have a significant abnormality of bladder function. This is caused by interruption of the normal nerve supply to the bladder by the spina bifida deformity.

Normally the bladder fills with urine, which relaxes to accommodate it. The muscle around the tube to the outside (urethral sphincter), at this stage, is contracted to prevent the escape of urine. Eventually, the bladder cannot relax any further and begins to contract. This results in the sensation which able bodied people get when they need to go to the toilet. When the bladder contracts, the urethral sphincter relaxes and the bladder empties itself, usually completely.

There are several different ways in which a bladder may be affected in spina bifida and each person affected by the disease is different. This may result in incontinence, urinary infections - or worse - damage to the kidneys.

URINARY SYSTEM (FEMALE)



For these reasons, it is important that a child is identified early and is seen regularly by a specialist who can arrange the correct treatment. If this is not being done, consult your GP for further advice.

BLADDER PROBLEMS CAUSED BY SPINA BIFIDA

- **Loss of sensation**

Most people with spina bifida will have this problem. It affects the bladder as well as the tube leading from the bladder to the outside (urethra). The result is that the person does not know when the bladder is about to contract to expel urine. With the normal bladder this type of sensation will usually allow an indivdual time to get to a toilet and avoid accidents. However, when there is no bladder or urethral sensation, the first signs of passing urine will be after this has occurred, when it is too late.

- **Automatic or reflex bladder contractions**

Occasionally the nerves to the bladder and urethra are intact. But the signals which are normally conveyed to the person's brain, to tell when the bladder is full, are blocked because of the spina bifida abnormality. The bladder will contract and the urethral sphincter relax in the normal way, but the person does not get any warning that they are about to pass urine and are incontinent.

- **Paralysis of the bladder muscle**

This can result in a bladder which either cannot contract strongly or is continuously in a state of spasm. In the former, because the bladder cannot empty itself completely, there is stagnation of urine which will result in infection. In the latter, the capacity of the bladder is greatly reduced and the person passes urine in small quantities very frequently.

- **Paralysis of the urethral sphincter**

Just like bladder muscle, the urethral sphincter may either be unable to contract or it may be unable to relax. If it cannot contract, then urine will drain from the bladder, even if the pressure in the bladder is low. This will result in urine leaking away when the person coughs or laughs. If the sphincter is continuously contracted, then urine will drain from the bladder only under high pressure. This usually results in incomplete bladder emptying and, as a result, stagnation of urine and infection.

CONSEQUENCES OF ABNORMAL BLADDER FUNCTION

- **Incontinence**

Without sensation it is impossible to anticipate the need to go to the toilet and wetting will result. However, with correct treatment, it is usually possible to achieve satisfactory continence of urine. Even though a child with spina bifida may apparently be able to stay dry for many hours, it should not be assumed that bladder function is normal. Indeed, these people may have bladders which are most likely to cause serious damage to the kidneys and require the closest supervision.

- **Reflux of urine from the bladder to the kidney**

This results from abnormal control of bladder contraction and, in particular, occurs when

ANAGEMENT

the pressure inside the bladder is abnormally high. The urine which refluxes up to the kidneys will not be passed to the outside and will stagnate, increasing the risk of infection. A combination of infection and high pressure will damage the kidneys and this problem requires urgent treatment to avoid long-term difficulties.

- **Urinary tract infection**

Stagnation due to incomplete bladder emptying will lead to infection. Providing reflux is not present, this infection is unlikely to cause harm, but may increase problems with continence and cause an unpleasant smell. Treatment, apart from antibiotics, is directed at reducing stagnation of urine.

TYPES OF TREATMENT

Treatment, from the doctor's point of view, is aimed at reducing the pressure inside the bladder, reducing stagnation of urine (thus reducing the risk of infection) and, lastly, increasing the chance of continence - in that order of importance. From the point of view of the individual who has the problem and their family, continence is usually the priority - but the risks of damage to the kidneys should not be forgotten.

- **Clean intermittent catheterisation (CIC)**

A tube (catheter) is passed into the bladder, which is emptied. This is done, preferably, by the affected person, if this is possible. Usually after a period of about three hours, just before the bladder begins to leak, the catheter is passed again. If bladder capacity is too small or the urethral sphincter is too weak, there are drugs and operations which will improve this situation.

- **Continuous catheter drainage**

Where CIC is technically impossible, the bladder can be drained by a catheter which is left in permanently and changed from time to time. The disadvantage compared to CIC is that the catheter may in itself predispose to infection.

CIC and continuous catheter drainage will:

- reduce the wetting, often with complete dryness day and night;
- empty the bladder, which reduces the chances of acquiring a urinary infection - though the predisposition to infection is always present with continuous catheter drainage;
- reduce the pressure on the kidneys by emptying the bladder;
- often cure reflux from the bladder to the kidneys.

- **Urinary diversion**

If CIC or continuous catheter drainage is not appropriate, an operation may be necessary to ensure adequate drainage of urine under low pressure. This can take several forms which are described as urinary diversion operations. This means that the urine is diverted away from the bladder or urethra, usually on to the surface of the abdominal wall, into a bag. These operations are not commonly used nowadays, but are sometimes necessary to protect the kidneys of those who are at greater than normal risk of damage.

More common now are continent stomas (eg Mitrofanoff). This is an operation which provides the individual with a catheterisable stoma on the abdominal wall which does not need a bag. This can be an option when dexterity/mobility is a problem.

- **Increase bladder capacity**

There are drugs which will cause the bladder to relax if the major problem is continuous spasm. These can be by mouth or intravesicular (ie through the catheter). However, sometimes even these powerful agents will not increase the volume of the bladder sufficiently. In these cases, an operation can be performed to put a short piece of intestine on top of the bladder to increase its size (bladder augmentation).

- **Increase the pressure at which urine flows through the urethra**

If the urethral sphincter is paralysed and is not contracting, then urine will leak under low pressure. Drugs are available which will increase the contraction of the muscle in the urethra. Often, however, an operation will be necessary to either tighten the urethra or to insert an artificial sphincter, which can be controlled by the person themselves. These treatments are usually used in combination with CIC.

CONCLUSION

There is no single approach to bladder management. What is suitable for one person may not be suitable for another. It is important for individuals to be assessed from birth and regularly thereafter. Control of continence may have to be achieved by a mixture of treatments depending on which abnormalities are present.

- Take advice from your paediatrician and/or urologist.
- When in doubt, ask for the help of an experienced continence adviser.
- Begin treatment as early as possible (a daily care plan can be devised to suit the nursery, school/college or workplace day).
- Be patient and persistent.

At ASBAH, we understand the needs of our client group and are ready to give advice and support.

PIGEON POWER

Five Oaks, ASBAH's independence training centre in Yorkshire, has just taken delivery of a brand new, wheelchair adapted minibus - and it's all due to Britain's pigeon racers.

Over the years, the British Homing World 'Show of the Year,' organised by the Royal Pigeon Racing Association, has raised a staggering £160,000 for ASBAH, through its raffles and entry fees to the show. This year their generosity took a different form in the donation of the bus for Five Oaks.

Joan Pheasant, manager of Five Oaks, told us: "The bus will be used every day. It will be especially useful for those on extended training courses at Five Oaks, to take them everywhere from shopping to sports trips."

The Centre had already launched an appeal for a new bus when the pigeon racers presented their gift and, with donations from local trusts still coming in, Five Oaks should be able to purchase a second vehicle later this year.

Left: All aboard - Joan Pheasant shows the keys to her 'passengers'.

HOLIDAYS REVIEW

Each month the BBC 'Holiday' programme will be reviewing the holidays it has featured and giving information on their accessibility for disabled travellers. They hope to encourage tour companies to "try harder" to make their holidays available to all.

The programme will be producing a booklet giving information on access to holidays as well as more general information for the disabled holidaymaker. For a free copy, send a large SAE to: Disabled Traveller, PO Box 7, London W3 6XJ.

PUBLICATIONS

Holidays in the British Isles 1992 - A Guide for Disabled People - is the latest edition of RADAR's annual book with information on voluntary and commercial organisations which provide holidays for disabled people. This year the range of accommodation included in the guide is wider - hotels, guest houses, self-catering cottages and flats, colleges, camping and caravan sites, holiday parks and specialist centres.

Available, from RADAR at 25 Mortimer Street, London W1N 8AB, it is priced at £4.50, including post & packing.

FIVE OAKS IN THE NEWS

A crew from Yorkshire Television visited Five Oaks in December to make a short film on the work of the training centre. The film clip was featured on one night, in a week long Toy Appeal shown on a local ITV news programme. As a result of the appeal Five Oaks is hoping to obtain some computer equipment.

Orange Badge Changes come into force

Amendments to the regulations for Orange Badges will become law on 2 March 1992.

- A new style badge has been designed which will carry a photograph of the holder to prevent misuse. The picture will be on the inside of the badge so that it will not show when placed in the window of the vehicle but a police officer or traffic warden could ask to see the badge to check that it is being used by the person entitled to do so.
- If the badge is used by anyone other than the bona fide holder there is a maximum penalty of £400, which will increase to £1000 when the Criminal Justice Act 1991 comes into force.
- The time limit for parking on single or double yellow lines, using the badge, will increase from two to three hours.
- Those in receipt of Mobility Allowance will have automatic entitlement to a Badge.
- More guidance will be available to issuing authorities in administering the scheme.
- Consultation will continue with local authorities to ensure that only those entitled to receive Orange badges do so.

Holiday Information and Advice

The Holiday Care Service offers a free holiday information and advice service for people with disabilities. Whatever kind of holiday you want they should be able to help: "We carry information on the whole world...on activity holidays, special interest etc," said their director, Maundy Todd.

For those holidaying in the UK, HCS produces a series of guides on 'Accessible Accommodation' (the 1992 booklets will be published shortly). Each booklet covers a Regional Tourist Board area - The Heart of England, The West Country, Cumbria, Scotland, Wales, and so on. The HCS inspects all the establishments listed.

Other services from HCS include the provision of a volunteer helper to accompany a disabled holidaymaker and a comprehensive travel insurance policy which is specifically designed to cover most pre-existing medical conditions.

Further information from: Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW, telephone 0293 774535.

THE BEST DAYS OF YOUR LIFE

Choosing a school to suit your child's needs can be a difficult task, and parents will already be thinking about schooling for September.

The Lord Mayor Treloar College is a residential school in Hampshire which takes pupils from seven to 19 years old, from all over the country - a large proportion of whom have spina bifida and/or hydrocephalus.

The College is a non-maintained school and fees are usually paid by the pupil's Local Education Authority. It is a school for pupils with any kind of physical disability and has a medical centre on each of its two sites. There are also physiotherapists and counsellors on the staff.

All core and foundation subjects of the National Curriculum are offered, there is a high ratio of teachers to students and classes are small. Sport and drama are well catered for at the college.

Visits to the school for prospective students and their parents, take place every Tuesday, so to find out more or arrange a visit, contact them at Holybourne, Alton, Hampshire GU34 4EN, telephone 0420 83508.

Look what they have to offer

You could take a break on one of the many holidays or activities on offer at Five Oaks this year - and see their new bus and equipment for yourself!

Their new colour brochure for 1992-93 is out now and details the variety of breaks available: bird watching, fashion, outdoor pursuits, fishing or just relaxing - the choice is yours.

You can book now for a 'Day Tripper' week in March - each day you pick a different trip - to the coast, a canal cruise, an outing to the cinema, bowling, a day at the races, or even skiing.

Five Oaks also runs 'Holiday Weeks' during school holiday periods, the first of these is at Easter.

For a copy of the brochure, or to book a place, contact: Sarah Peet, Five Oaks Centre, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, telephone 0943 603013.

Diary dates

9 MARCH: AGM Northern Ireland ASBAH, Chimney Corner restaurant, Belfast, 8pm. Guest speaker, Mrs Valerie Moore (vice-president, European Union for Hydrocephalus & Spina Bifida).

13 MARCH: Housing - A Question of Influence. A RADAR conference on the problems experienced by service providers, policy makers and disabled people in housing. At RIBA, Portland Place, London. Details, Rachel Scott, Conference Officer, RADAR, 25 Mortimer Street, London W1N 8AB. 071 637 5400.

20-22 MARCH: Northern Ireland ASBAH Respite Care Weekend, Portrush. Information, Jimmy Rippey, 06487 62290.

24 MARCH: Sexuality and Disability - a one day seminar for young adults, at Westminster Hospital, London. More details from Maddie Blackburn, 081 746 8631.

28 MARCH: Continence in Spina Bifida - a study day for parents and professionals, sponsored by Reading Friends of ASBAH. At Royal Berkshire Hospital Club, 22 Craven Road, Reading. Details from Liz Clayton, 0734 724013.

10 APRIL: Charity Ball at Belfast City Hall. 7.30pm - 1am in aid of Northern Ireland ASBAH. Tickets £25 each from Mr Jimmy Rippey, 064 87 62290.

MAY 7: ASBAH Symposium for professionals. Topics related to spina bifida and hydrocephalus. Peterborough Central Library.

MAY 21: Continence Management Study Day. For professionals, at Peterborough Central Library. Fee £30. Contact Lynn/Rolanda at ASBAH, 0733 555988.

LOOKING AT OUR Image

How do young people with spina bifida see themselves? How can we help promote a good self image and independence in these youngsters? These are just two of the questions being addressed in a current ASBAH research project. Dr Philip Minchom and Mr Peter Appleton take us through the background and aims of their research.

The project

The Wrexham project to research the self image of young people with spina bifida stems from the practical problems facing members of our team as they work with young people with spina bifida. In trying to help them achieve skills in independence it became evident that we had only our own perspective on living with a disability. We needed to know how they regarded themselves and their problems. The project is undertaking detailed questionnaires with 80 children and young people with spina bifida. Psychological, social, occupational therapy and medical assessments are being carried out and the responses compared with a control group of 80 able bodied youngsters.

What effect does disability management have on a person's self image?

The management of complex disability often requires the juggling of several interrelated medical, social and psychological problems. Sometimes it seems that rather than a co-ordinated approach the hopeful philosophy is "get all the bits right and the whole will work". But is there a better approach to ensuring that all advances in management of disability in spina bifida are allowed to be effective in promoting independence? How often is the particular aspect of disability under scrutiny related to a view of the whole individual? At its simplest, how often are the patient's own views taken into account: "I had a back and hip operations and they were failures. I never understand why I have to go through all these operations..no one tells me anything...it's as though I am not here half of the time."

Treatment programmes could be organised not merely along the lines dictated by the professionals but could reflect the perceptions, wishes, and needs of the individuals. Treatment may then become truly holistic. For a good self image young people also need the skills for independent management of their own lives. The skills and the method of teaching must allow for the self perception and image of the student to work effectively. It may not be logical to base training programmes on those which are successful with able bodied people. Success will depend on aligning the training to the self concept (self worth, self esteem) of the child. Until we have systematically assessed these subtle concepts as they manifest in young people with spina bifida, training will be problematic.

There are rather more questions than answers on how to achieve successful independence skills in young people with physical disability and we do not pretend that we have the answers. We cannot claim sophistication in approaching the problems in everyday practice. There is an urgent need for the research to give the guidelines for success in the future.

Which factors affect self-image?

What we need to know is the sorts of factors in young people's lives which lead them to have low self-esteem and those which promote self-esteem. With this knowledge we will understand more about the kinds of opportunities which need to be created for young people which may help them feel more confident about themselves and their futures. Some of these factors will be the same as those in able bodied children and will emphasise that we are working with children first, disability second. Other factors will be specific to being disabled.

Lots of research has been done into the determinants of self worth in able bodied young people. Our research is designed to find out whether these are also determinants in young people with spina bifida and hydrocephalus and if so how important they are in determining self worth, compared with their effect on able bodied people.

The first factor is that of how valued the young person feels by parents, classmates, friends, teachers and other professionals. Interestingly, it has been shown that the attitude of classmates is more important for self-worth than that of friends. If this is found to be true for young people with spina bifida it will make us think very carefully about the sorts of classroom settings and social arrangements they experience.

The second key factor, with able bodied young people, is how well they feel they are doing in areas of their lives which are important to them as individuals - relationships, schoolwork and physical appearance - for example.

The third determinant of self-worth, in studies of able bodied youngsters, is that of how good the young person feels, compared with peers, in areas of their lives which are important to them. Who do young people with spina bifida and hydrocephalus compare themselves to when they are thinking about their school activities and their social activities? Is it other physically disabled young people or is it able-bodied peers? What are the consequences of these thought processes? Our research will help us to understand this.

The fourth factor, which was found to be an extremely important determinant of general self-worth in able bodied young people, was that of how good they feel about their body. What is the impact of this on young people with spina bifida and hydrocephalus? Many people working with physically disabled young people feel that this is a central issue and we hope to throw light on it through the results of our research. We have taken special care to separate the measures of how a child feels about his/her body from the measure of how they feel about themselves as a whole person. One of the problems about previous research was that these two measures were confounded and therefore it was not possible to understand the effects of each upon the other.

The final factor is that of not blaming yourself for problems which are outside your control. Self blame and guilt can be linked to depression and we are studying this in both physically disabled and able bodied young people to see whether there are any differences in emphasis.

Aspirations

We hope that the results of our research (expected later this year) will help to guide some of the changes that are taking place in the provision of opportunities and services for young people with spina bifida and hydrocephalus.

The research will give clues about the sorts of opportunities, challenges and experiences which are likely to lead to a more positive sense of self-worth. The findings will help us to rethink interventions that involve the young person's body (eg surgery, mobility and continence training) and to consider the young person's views and feelings.

Finally, we expect to highlight particular sources of distress and sadness and hope that this information will also be useful in the development of appropriately balanced services.

This article is a summary of a talk given by Dr Minchom and Mr Appleton at ASBAH's AGM in October. The title of the research is 'Image and Self Concept in Children and Young People with Spina Bifida'. Mr Appleton is a clinical psychologist and Dr Minchom is a paediatrician, Paediatric Department, Wrexham Maelor Hospital, Croesnewydd Road, Wrexham, Clwyd LL13 7TD. The core research team also consists of Vicki Boll, Pat Jones and Dr Nick Ellis of the University of Wales.

Letters

Could you help?

I am a freelance writer and I am planning to write a book specifically concerned with women who have had terminations for abnormality, some of whom I would hope have had subsequent successful pregnancies. I want to write their stories, not a medical tome concerning how or why the problem might have occurred.

My experience of an anencaphalic pregnancy and of miscarriage will be included, but obviously it will not be enough. At present I am trying to trace women and their partners who would be willing to share their tragedy with me either by means of a questionnaire that I am compiling at present, or in their own words.

I realise that this will provoke many painful emotions and memories. It is not something that I will find easy. The grief I feel is still very strong. However, couples that I have spoken to so far have expressed both interest and a great need for such a book.

If you could help me in any way, I would be extremely grateful. I assure those who may feel able to take part of complete confidentiality at all times. Please write to me at P O Box 122, Roanoke, TX 762262, USA, or c/o Publicity Manager at ASBAH House.

Susan Bell
Texas, USA

French exchange

We have recently had an enquiry from a French friend of ours who teaches in a school for children with physical disabilities. A 14-year-old girl, with spina bifida, who is in the third form of her school, would love to have an English penfriend; preferably with the same disability.

Noemie Vermeule lives in France. She has a brother aged 13 and a sister aged 17. Noemie enjoys music and plays the flute and violin. She is a wheelchair user and is quite self-reliant.

Noemie's parents are supportive and keen to arrange an exchange with an English pen-friend.

Sue Hawkett
London

If you would like to contact Neomie you can send your letters to LINK and we will pass them to Mrs Hawkett.

Information Technology and Special Needs

PETER WALKER looks at how useful computers can be as a learning aid for children with special needs and gives some useful contacts in this field.

Many children with spina bifida and/or hydrocephalus experience difficulties in some of these areas: reading, spelling, handwriting, sequencing, visual discrimination, memory, motivation and organisational skills. Computers with the appropriate programmes can greatly assist learners who are struggling to make progress.

Information technology can support effective learning in all areas of the curriculum. Word processors allow the student to produce clear writing and to amend, print, review and revise work. The use of a spell checker can help with spelling difficulties by highlighting words it does not recognise for the writer to check. It may also offer alternative suggestions. Programmes which use 'cloze' procedures - which is essentially a text with words omitted at regular intervals - can help to identify learners' strengths or weaknesses. Such programmes may also help them to improve their recognition of word shapes and common letter strings.

Word processors can enable learners to take notes and organise them more effectively, make work plans using diagrams, flow charts, headings and key words. All these are planning tools which can form an essential part of a successful writing strategy. Specific skills training, using either drill and practice letter recognition or the writing of meaningful and relevant material, can be developed by using a word processor. In addition there are a number of activities that can help in developing memory skills.

For older pupils, in secondary schools, lap top computers and cassette recorders can greatly help with the chore of note taking and the preparation and presentation of school and home work. Technology for many pupils with special educational needs can provide an excellent means of enhancing competence, self-esteem and presentation of work.

Useful contacts

The ACE Centre, Ormond Street, Wayneflete Road, Headington, Oxford OX3 8DD, telephone 0865 63508. This centre assesses children with communication difficulties and recommends suitable technology. They also produce a range of information sheets and publish reports on such topics as: introductory software, word processors and portable computers.

The BDA Computer Resource Centre, Department of Psychology, University of Hull, Hull HU6 7RX, telephone 0482 465388. The BDA centre contains a wide range of software which learners with dyslexia have found to be of value. Teachers or parents can visit the centre (by appointment) or write/phone with any queries.

National Federation of ACCESS Centres, Janis Firminger, Hereward College of Further Education, Branston Crescent, Tile Hill, Coventry CV4 9SW, telephone 0203 461231. The National Federation is a nationwide group of further education establishments, which assess adult students and recommend suitable software and aids. They undertake assessments for the Open University and for local Education Authorities and have recently begun to help students with specific learning difficulties.

National Council for Educational Technology, Sir William Lyons Road, University of Warwick, Science Park, Coventry, CV4 7EZ, telephone 0203 416 994. This Council was set up by the DES in April 1988: "to promote the use of new and existing technologies to enhance learning opportunities in all areas of education and training".

It works with organisations and networks to provide advice, support, information, training and some research. It offers a comprehensive range of information sheets and support materials for teachers and produces a range of packs and other publications. The Special Needs Section tries to monitor and evaluate the use of informative techniques in special needs provision in mainstream, special schools and colleges.

Right: A student at Hereward College uses a large monitor to give a bigger text on screen.

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 (April) should be submitted by Friday,6 March. 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.

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, Brimstead, Ryde PO33 3PX

SUNNY TENERIFE or SCENIC NORTH WALES

mar y sol

Holiday apartments at beautiful, fully accessible 'MAR Y SOL' Los Cristianos. "Brilliant, Amazing," say the BBC's Travel Show. Flights arranged. Also luxury adapted bungalow (sleeps 4/5) in Mold, Clwyd. Brochures: Lynne James Ltd., 7 Overpool Road, Ellesmore Port, South Wirral L66 1JW (Tel: 051 339 5316)

BLUE ANCHOR, NEAR MINEHEAD

Privately situated self-catering bungalows fully accessible fully equipped with linen, T.V., video games room, laundry, parking, playground, splendid views of sea, Exmoor, steam railway. Phone: Lorraine or Martyn Babb, Dunster (0643) 821200)

FOR SALE

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.

SEMINAR

'Sexuality and Disability'

A one-day seminar for young adults with spina bifida and hydrocephalus, carers and health professionals.

To include presentation of an introductory training video and leaflets on issues related to sexuality.

Date - **Tuesday, 24 March, 1992**

Time - **10am-3.30pm**

Venue - **Westminster Hospital, Page Street Lecture Theatre, Page Street, London SW1.**

(Wheelchair accessible facilities)

Travel allowance and lunch/ refreshments provided

Contributors include: **Dr Martin Bax,** Chairman Medical Advisory Committee ASBAH; **Maddie Blackburn,** Research Fellow ASBAH; **Mrs Pat Edser,** formerly Co-ordinator National Counselling Service ASBAH; **Alan Hannah,** Legal Adviser Sexuality and Disability Research Project.

Further information and application form from Maddie Blackburn or Yvonne Hunt, tel 081 746 8631 or 8629, or write to: Community Paediatric Research Unit, Westminster Children's Hospital, 144-146 Vauxhall Bridge Road, London SW1.

DIRECTORY OF LOCAL ASSOCIATIONS

BARNSLEY
Mrs Marlene Haigh,
3a Birk Avenue,
Kendray,
Barnsley, S Yorks S70 3AE

BEDFORD
Mrs Elsie Bennett,
341 Bedford Road,
Kempston, Beds MK42 8PX

BOURNEMOUTH, CHRISTCHURCH & DISTICT
Mrs G. Lanning,
23 Seaway Avenue,
Christchurch, Dorset
Tel: 0425 273 255

BRISTOL & DISTRICT
Mr G Egan,
64 Rookery Road,
Knowle, Bristol 4
Tel: 0272 777942

BUCKS & E.BERKS
Mrs M Ross,
19 Sheepcote Cottages,
Sheepcote Dell Road,
Holmer Green,
High Wycombe,
Bucks HP15 6TJ

BURY & BOLTON
Mr David Clyne,
51 Cuckoo Lane,
Whitefield,
Manchester M25 5WQ
Tel: 061 798 7804 (after 4 pm)

CALDERDALE
Mr A L Crowther,
12 Elm View,
Huddersfield Road,
Halifax HX3 OAE
Tel: 0422 341497

CAMBRIDGESHIRE
Mrs D Thorn,
55 Hanbury,
Orton Goldhay,
Peterborough,
PE2 0QU
Tel: 0733 235139

CHESTER & DISTRICT
Mrs P Ithell,
34 King Edward Street,
Shotton, Deeside
Tel: 0244 811074

COVENTRY
Mrs N Newman
11 The Earls Croft
Cheylesmere
Coventry CV3 5ES

DUDLEY, WOLVERHAMPTON & SANDWELL
Mrs Lorna J Wootton,
14 Leveson Road,
Wednesfield, Wolverhampton,
West Midlands, WV11 2HF
Tel: 0902 738724

ESSEX
Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex 1G3 9AX
Tel: 081 594 1852

GLOUCESTERSHIRE
Mrs J A Wintle,
54 Borough Close,
Kings Stanley
Stonehouse, Glos GL10 3LJ
Tel: 045 382 2963

GRANTHAM
Miss Caroline MacCallum,
58 Redcross Street,
Grantham, Lincs NG31 8BU
Tel: 0476 66085

GREENWICH
Mrs M Mears,
29 Wellmeadow Road,
London SE13 65Y
Tel: 081 698 5567

HAMPSHIRE NORTH, W SURREY & S BERKS
Mrs Liz Selby,
Buryfields House,
Buryfields
Guildford, Surrey GU2 5AZ
Tel: 0483 571736

HAMPSHIRE SOUTH
Mr S R Baker,
12 Moorings Way,
Southsea; Portsmouth, Hants
POY 8QW
Tel: 0705 819075

HERTS & S BEDS
Mrs S Riseborough,
4 Sherborne Way,
Croxley Green, Rickmansworth,
Herts WD3 3PF.

HILLINGDON
Mrs B Brannen,
30 Fairey Avenue,
Hayes, Middlesex

HUDDERSFIELD
Mrs J V Brook,
11 Standiforth Road, Dalton
Huddersfield
Tel: 0484 421776

HULL & DISTRICT
Mrs G D Brown,
233 Cranbrook Avenue,
Hull HU6 7TX
Tel: 0482 857165

JERSEY, Channel Islands
Mrs Joy Thomas,
Belles Roches Cottage,
Vallees des Vaux,
St Helier, Jersey, C.I.

KENT
Mrs S Weatherstone
6 Croftside
Vigo Village
Meopham Kent DA13 0SH
Tel: 0732 822985

LEEDS & BRADFORD
Mrs Anne Grange,
Five Oaks Ben Rhydding Drive,
Ilkley, West Yorkshire LS29 8BD
Tel: Ilkley 609468

LINCOLN & MID LINCS
Mrs P Malson,
"Pinfold", Chapel Lane,
North Scarle, Lincoln LN6 9EX
Tel: 0522 77781

LEICESTERSHIRE
Mrs A Twomlow,
29 The Crescent
Market Harborough
Leicestershire LE16 7JJ
Tel: 0858 32967

LINCOLNSHIRE SOUTH
Mrs P Mason,
67 Boston Road,
Heckington, Sleaford, Lincs

LONDON N.EAST
Mrs B A Pierson,
18 Kingsley Road,
Forest Gate,
London E7 9PP
Tel: 081 472 8605

LONDON N WEST
Mrs H Prentice,
37 Milton Road,
Hanwell, London W7 ILQ

LONDON SOUTH
Mrs S Cudd,
15 Woodvale Walk,
Elder Road, W Norwood,
London SE27
Tel: 081 761 2400

MANCHESTER CENTRAL
Miss Alison McCormack,
100 Heaton Park Road,
Higher Blackley,
Manchester 9, M9 3QQ
Tel: 061 740 6397

MIDLAND
Mrs D Britt,
14 Court Road,
Sparkhill, Birmingham 11
Tel: 021 771 0371

NORTH EAST (Northumberland)
Mrs E Grant,
27 Redwell Road,
Prudhoe,
Northumberland

NORTHAMPTONSHIRE
Mrs J Cockings,
57 Little Street,
Rushden,
Northants

OXFORDSHIRE
Mrs Shirley Dale,
14 South Row, Chilton,
Didcot, Oxon

PRESTON
Mrs S Thompson,
34 Beatty Road,
Southport, Merseyside,
PR8 6LB

ROTHERHAM & DONCASTER
Mrs Katie Hemmings
40 Bentley Road
Bentley
Doncaster
DN5 9TA

ST HELENS & DISTRICT
Mrs N Maddocks,
236 Rainhill Road,
Prescot,
Merseyside L35 4LD
Tel: 051 426 3921

SALISBURY & DISTRICT
Mrs J Renshaw,
1 Philip Court,
Coronation Road,
Salisbury SP2 9DA

SHEFFIELD
Mrs C Crofts,
46 Busheywood Road,
Sheffield S17 3QB
Tel: 0742 366033

SOMERSET
Miss June Roberts,
18 Spicer Way,
Chard,
Somerset TA20 2JS

SOUTH THAMES
Mr Charles Harper,
7 Eresby Drive,
Beckenham BR3 3LS
Tel: 081 777 1182

SOUTHAMPTON & DISTRICT
Mr A D Strong,
8 Summerfields,
Locks Heath,
Southampton,
SO3 6NN
Tel: 042121 2644

STAFFORDSHIRE
Mrs J Davies,
8 Oakhill Avenue,
Oakhill,
Stoke-on-Trent ST4 5NJ
Tel: 0782 45365

STOCKPORT
Mrs J Roberts,
9 Highcroft Road,
Romiley, Stockport,
Cheshire SK6 4PS
Tel: 061 430 4869

SUFFOLK
Mrs Mary Myers,
59 Lisburn Road,
Newmarket,
Suffolk CB8 8HS
Tel: 0638 661873

SUNDERLAND
Mrs Audrie Shepherd,
115 Holborn Road,
Sunderland
Tel: 091 528 3568

SURREY
Mr Simon Figg,
4 Brickyard Copse,
Ockley,
Dorking,
Surrey RH5 5TJ
Tel: 030679 572

SUSSEX
Mrs M White,
Averys,
Rusper, Horsham,
Sussex
Tel: 0293 871217

TRAFFORD & SALFORD
Mrs T Gaynor,
Davis Court,
Cyprus Street,
Stretford, Manchester M32 8AX
Tel: 061 865 0222 mornings only

WARRINGTON & DISTRICT
Mrs S Lawless,
4 Astley Close,
Warrington,
Cheshire WA4 6RB
Tel: 0925 573708

WESSEX
Mr T Poole,
123 Gerrards Green,
Beaminster,
Dorset DT8 3EA
Tel: 0308 862614

WHITCHURCH & DISTRICT
Mrs D R Calder,
3a Bridgewater Road,
Whitchurch, Shropshire

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeon,
24 Greendale Crescent,
Leigh, WN7 2LQ
Tel: 0942 676091

WIRRAL
Mrs M Hudson,
28 Stavordale Road,
Moreton, Wirral, Cheshire
L46 9PR

WORCESTERSHIRE
Mrs C Sheppard,
37 Greenacres Road,
St Johns, Worcester,
WR2 5EZ
Tel: 0905 421581

YORKSHIRE NORTH
Miss Faith Seward, MBE, BA,
45 The Paddock,
York YO2 6AW
Tel: 0904 798653

WALES

Llanelli
Mrs Anthea James,
61 Westland Close,
Loughor,
Swansea SA4 2JT.

Mid Wales
Mrs J Carter,
1 Meadow Road,
Craven Arms,
Shropshire SY7 9QY

North Wales
Mrs L D Morris,
Penrhyn Arms,
Pendre Road,
Penrhynside,
Llandudno LL30 3BY

South Wales
Mrs Brenda Sharp,
38 Redbrink Crescent,
Barry Island,
S Glamorgan,
Tel: 0446 735714

NORTHERN IRELAND

Mr J Rippey,
Long Eaves,
24 Tulleywiggan Road,
Cookstown,
Co Tyrone
Tel: 064 87 62290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mrs Heather Pullin,
74 Newton Drive,
Blackpool FY3 8EP
Tel: 0253 396256

Cannock & Walsall
Mr Ken Hall,
17 Wallhouse Street,
Cannock, Staffs
Tel: 054 35 4847

Chesterfield
Mrs K M Tomlinson,
23 Hathern Close,
Brimington Common,
Chesterfield, Derbys

Cornwall
Mrs Wendy James,
17 Pergegon Parc,
Camborne, Cornwall
Tel: 0209 712191

Consett & District
M Broadley,
15 Girvan Close,
Burnside, E Stanley,
Stanley, Co Durham

Derby & District
Mrs A Hewitt,
St Merryn,
20 Burley Hill,
Allestree, Derby

East Anglia
Mrs L A Turner,
22 Windsor Drive,
Wisbech, Cambs
Tel: 0945 64483

Gainsborough & District
Mrs M Hawkes,
10 Turpin Close,
Gainsborough,
Lincs DN21 1PA
Tel: 0427 616807

Isle of Wight
Mr D J S Sprake,
Springfield, Town Lane,
Chale Green, Ventnor,
I W
Tel: Chale Green 234

Lancaster, Morecambe & District
Mrs Dyson,
25 Royds Avenue,
Heysham,
Morecambe LA3 1PA

Rochdale
Mrs Ann Lawton,
20 Spencer Street,
Chadderton, Odham, Lancs
Tel: 061 6524487

Teesside
Mr J Gray,
Marchesi Centre,
Tollesby Road,
Middlesbrough, Teesside
Tel: 0642 814458

West Wales
Mr Bob Tuckey,
Goldborough Farm,
Hundleton, Pembroke,
Dyfed SA71 5TR

OTHER ASSOCIATIONS

SCOTTISH

Executive Officer:
Mr Andrew Wynd,
190 Queensferry Road,
Edinburgh EH4 2BW
Tel: 031 332 0743

IRISH

The Secretary,
Irish ASBAH,
Old Nangor Road,
Clondalkin, Dublin 22
Tel: Dublin 01-572326