

June/July 1993

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Opinion



NEW legal requirements for community care have been in force since the beginning of April, when local social services departments took over as lead agencies, to arrange services for those with special needs.

ASBAH is concerned that disability is not a high priority, but we remind readers that the new set-up has been designed to respond to demand.

Our advice to disabled individuals, to carers and to local associations is **BE DEMANDING!**

We can advise and do our best to guide you and support your demands, with information on your rights under law and on the new regulations.

Any local association wishing to be more effective locally, to influence your local and health authorities, please contact the

Executive Director, as we would like to offer you all the help we can.

TALKING of being demanding, read inside what Abe and Rosamine Hayeem had to do to get the right treatment for their daughter Judith's condition.

They scoured the world to find a neurosurgeon who could treat their daughter's particular condition and ended up living in Nottingham - near to a surgeon skilled and trained in the particular technique. Judith is now sitting exams for her second degree.

Freelance journalist Carmel Fitzsimons first told their story in 'The Independent on Sunday' a few weeks ago, and we have no hesitation in running it again.

Most of us do not have the

means to uproot and travel to another country to pursue the best treatment. We expect it to be available already.

EXPECTATIONS seem to count for little when parents of children with spina bifida try to obtain routine orthopaedic surgery for their children in Northern Ireland. The service, as we recount (not for the first time), is in danger of collapse again this summer.

The problem is that there are not enough orthopaedic surgeons to go round. The province's only paediatric orthopaedic specialist is swamped with other work. And the effects, as parent Pauline Clarke hints on our letters page, are probably far worse than anyone without an affected child can imagine.

Now, it seems, we have the promise of another surgical appointment from August, albeit at senior house officer level only. Let's hope, however, that it works and gets this vitally-needed service back on track.

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Cover: Barry Hussey in fine form:
see 'Crown Glory' page 7.

Photograph courtesy Birmingham Evening Mail.



'Don't hang up...'

Parents received a £1,500 quarterly phone bill after their son, who has hydrocephalus, talked for hours to a telephone sex chat line. But most of the bill was remitted after ASBAH kicked up a stink.

British Telecom knocked £1,330 off the bill, after a fieldworker complained that the young man involved had been enticed into talking longer than he wanted by a sex line operator whose motive was to increase her firm's profits.

Lynne Young, our fieldworker in Cornwall, criticised the operation of the chat line - one of BT's premium rate information and entertainment services - which she said had caused misery to the young man's parents.

She said the young man eventually admitted that, whenever he was

making these calls and wanted to put the phone down, the woman operator persuaded him to talk a little longer. One of the characteristics of hydrocephalus is that it can reduce sense of the passing of time.

In interviews with local media, Mrs Young urged all families to arrange for calls to be barred to the premium rate services if they were worried that the system was open to abuse. This is possible in areas where BT have opened their new digital telephone exchanges.

"People should not be complacent, thinking this sort of thing could never happen to them. It can and it does, and it causes untold misery" said Mrs Young.

When questioned, BT said the family's telephone meter was



Lynne Young

changed during the billing period, but the change was not logged properly. As a result, they had credited the family with £1,330 plus VAT.

Advice not getting through

Government advice on cutting the risks of babies being born with spina bifida has failed to reach most women at risk, the magazine *Which? way to Health* has reported.

Department of Health advice on increasing intake of the vital diet supplement has simply not reached seven out of ten (71%) potential mothers, according to a magazine survey published by the Consumers' Association.

Of those women (26%) who said they had heard the Government's advice to increase their intake of folic acid, only one in eight (3% of the total) could repeat the advice.

Folic acid is a vitamin found in green vegetables and fortified cereals and bread, and is available in some vitamin supplements.

The Government's advice in December was that all women of child-bearing age who could conceive should increase their intake of folic acid by eating foods rich in folates - such as broccoli, Brussels sprouts and spinach.

Folic acid supplements are recommended for women planning pregnancies and the supply should be continued until the 12th week. Women who conceive unexpectedly are advised to start taking supplements as soon as they discover they are pregnant.

"Official advice is clearly not getting to those who need it", said magazine editor David Dickinson. "This information is very important for women who could become pregnant. The critical

period is before many women know they are pregnant, and before they consult their doctor.

"A few simple steps could help reduce the 400 cases a year of babies born with spina bifida in the UK."

Even women who had heard about the advice could find it difficult to act upon, said *Which? way to Health*. When the magazine's shoppers in five different areas tried to buy folic acid supplements, only four out of 15 shops which were checked out sold the vitamins at the recommended dose.

The magazine carried out its survey in February this year, questioning 546 women aged between 16 and 46.

Conference sponsorship

A major healthcare supplies manufacturer wishes to support the work of disabled living adviser Mary White.

The manufacturer, Smith and Nephew, has become the main sponsor for Derby ASBAH's conferences for healthcare and education professionals which involve the interweaving of continence management in holistic approaches to physical and mental development.

ASBAH's multi-disciplinary approach to the continence management needs of people with spina bifida and hydrocephalus is seen by Smith and Nephew as a unique contribution to this field.

S & N previously sponsored Mrs White when she was given study leave last year to visit North America after winning a National Florence Nightingale Memorial Committee scholarship.

Derby ASBAH has already been involved with national ASBAH in setting up successful conferences and the arrangement will mean that the model can be transported

round the country. A number of conferences and study days are being programmed. Mrs White, who lives in Derbyshire, will continue to work as a member of ASBAH's three-person continence advisory service within the DLS Department, based at Peterborough.

Smith and Nephew is a major manufacturer of continence supplies but, said Mrs White: "This sponsorship will not compromise my professional integrity in any way. My approach stays exactly the same and I will be under no pressure to recommend or use their products."

Canada bound

A study tour to examine integrated education in Ontario, Canada, has been organised by ASBAH Northern Ireland coordinator Meta Harvey. She travelled to Canada in the middle of May.



Mrs Harvey is visiting schools in the Hamilton/Waterloo school boards areas where children with physical and mental disabilities are educated alongside their able-bodied peers.

"Ontario province had legislation regarding the education of children with special needs which in practice proved to be disappointing. This parallels with our own experience with the 1986 Education and Libraries Order", said Mrs Harvey before leaving.

"The Hamilton and Waterloo Boards abolished their special schools and went for a full-inclusion policy. The aim of my tour is to study how they achieved their ideal, and the results of their policy."

During her stay, Mrs Harvey was due to meet Ontario's leading thinker on the subject, Dr Marsha Forrest. She is director of the province's Centre for Integrated Studies. Mrs Harvey was also hoping to have discussions with Ontario Spina Bifida and Hydrocephalus Association.

The bursary was awarded by the Northern Ireland Voluntary Trust in association with the Joseph Rowntree Charitable Trust.

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Road fleet exerts buying power

Motability claims that it operates the biggest contract car hire fleet in Britain. At the last count, the organisation had 130,759 contract vehicles on the road.

Motability helps disabled people become mobile through its contract hire and HP schemes. In 1992, it took 60,794 of new cars registered in the UK - almost 4% of the total.

Ford was the most popular manufacturer with 45% of the market, followed by Vauxhall with almost 19% and Rover with 14%.

The organisation says its size gives it unique power to achieve favourable deals for its customers. They will benefit soon from a Code of Practice requiring dealers to provide agreed levels of service and access for disabled customers.

"Motability increasingly represents a very significant market sector for motor manufacturers. We hope this will allow us to maintain the extremely competitive deals we are able to offer disabled people", said vice-chairman Lord Sterling.



Links around London

TAPE versions of the Stationlink timetable are now available to visually impaired people from London Transport's unit for disabled passengers. Stationlink - LT's fully-accessible inter-station bus service - links central London's main line stations in a clockwise circular route.

The tape describes the nature of the hourly service and includes departure times from each stop.

The service is available for anyone to use - passengers with luggage, pushchairs or wheelchairs will find space on board.

Stations served are Paddington, Marylebone, Euston, St Pancras, King's Cross, Liverpool Street, Fenchurch Street, London Bridge, Waterloo, Victoria, Victoria Coach Station and returning to Paddington.

Unit for Disabled Passengers, London Transport, 55 Broadway, London SW1H 0BD (tel 071-222 5600).

Awareness week

Midland ASBAH is planning an awareness week from 14 to 21 August, with the help of a grant provided by BBC Children in Need. It is aimed "primarily for and about people with spina bifida and/or hydrocephalus".

The week-long event is being held at Prospect Hall, College Walk, Selly Oak, Birmingham. It is hoped the first weekend will be residential - allowing people over 18 to attend a mobility exhibition and sessions on relationships and self-esteem, as well as taking part in an evening social.

Small charges will be made to cover overnight stays and refreshments.

Different topics for the rest of the week will be wheelchair mobility, hydrocephalus, continence, lifeskills and post-school.

For programme, contact Geraldine Long or Diane Britt, tel 021 733 7810.

Folic acid products

Since *The Mail on Sunday* reported ASBAH's complaint that folic acid was not available in the 0.4mg dose in all chemists' shops, two firms have written to LINK to promote their products.

Solgar Vitamins Ltd produce 0.4mg folic acid tablets, which cost £2.25 for 100 tablets (about three months supply) and two other multivitamin preparations or combinations which contain folic acid but also promote general health.

These are PreNatal Nutrients and Megasorb B.

Prenatal Nutrients is a multivitamin/mineral formula which Solgar say has been developed specially for pregnant and lactating women. It includes 0.4mg folic acid in two tablets, and costs £4.69 for 60 tablets.

Megasorb B Complex is a combination of B vitamins, including 0.4mg folic acid, and costs £7.59 for 50 tablets.

An independent distributor called 'Taylor Made' retails a B complex containing 0.4mg folic acid - priced at £8.70 for 120 days supply. It is yeast free, in a blended vegetable base, and can be obtained by mail order.

Women in the 'at risk' groups should take a daily supplement of 4mg - ten times higher - which can only be prescribed by their doctors.

Try your local health food store or contact: Solgar Vitamins, Solgar House, Chiltern Commerce Centre, Asheridge Road, Chesham, Bucks HP5 2PY, tel 0494-791691; 'Taylor Made', 19a Green Hey, Much Hoole, Preston, Lancs, England PR4 4QH., tel 0772-614204.

Education advisory committee

AN EXPERT advisory committee has been set up by ASBAH to advise us on all educational matters relating to people with special educational needs.

The committee - expected to meet twice a year - will keep ASBAH's policy up to date and fully informed at a time of radical change. It held its first meeting at ASBAH House on 6 April.

Current issues include the passage of the Education Bill through Parliament and the proposed Code of Practice, therapy in schools, and the discussion of an Integration Charter promoted by the Centre for Studies on Integration in Education.

The distinguished membership is:

Austin Crowther, vice-chairman of ASBAH; *Stephen Dorner*, a clinical psychologist at Havant; *Chester Gold*, headteacher of a special school in Sheffield; *Patricia Kennedy*, head occupational therapist at the Queen Elizabeth Hospital for Children in London;

Anthony Lonton, recently retired lecturer at the Centre for Educational Guidance and Special Needs in Manchester; *David Mallen*, county education officer for East Sussex; *Christopher Robertson*, lecturer in special educational needs at the London Institute of Education;

Lewis Rosenbloom, consultant paediatric neurologist at Alder Hey Children's Hospital in Liverpool; *Philippa Russell*, director of the Council for Disabled Children; *Carole Sobkowiak*, superintendent physiotherapist at Darlington Memorial Hospital;

Philippa Stobbs, education policy officer with the Council for

Disabled Children who is deeply involved with the Special Educational Consortium set up to co-ordinate the views of voluntary organisations during the debate on the Education Bill; and *Neil Watts*, headteacher of Northgate High School in Ipswich.

Mr Crowther, Mrs Russell and Mr Watts are all parents of young people with spina bifida and/or hydrocephalus.

ASBAH chairman *Patrick Daunt* acted as chairman for the first meeting in April. Education adviser *Peter Walker* and executive director *Andrew Russell* will attend all meetings.

Diploma course



This October, Leeds University will launch its first part-time course for professionals in the general area of disability - leading up to a Diploma in Disability Studies.

Participants will be required to attend on only one afternoon a week over two terms (14 weeks altogether) - so studies can be fitted round a busy working life.

Course organisers hope the diploma will be attractive to people like educational psychologists, therapists, social workers, community nurses, doctors, architects and town planners.

"The increasing prevalence and visibility of disability makes it one of the major socio-economic issues of our time, presenting far-reaching challenges for all those involved in policy, planning and the delivery of services", they say.

"This course will give students the knowledge and skills to meet those challenges."

Details: *Sheila Speedy*, Department of Continuing Professional Education, Continuing Education Building, Springfield Mount, Leeds LS2 9NG

Charities and community care - survey

Local health and social services have in general not helped voluntary organisations prepare for change under the new Community Care regime which came into force on 1 April.

That was the key finding of a snapshot survey of 151 charities involved in community care undertaken by London-based Monica Hart Press and Public Relations, a key player in consultancy to the voluntary sector.

Their survey - which included ASBAH - showed that the move to contracts is very patchy and, while good experiences were reported, there is still great uncertainty facing charities.

Less than half of the charities canvassed were optimistic about how they would cope with providing community care in the future. Only a third had entered into community care contracts, and nearly two-fifths were unsure how they stood financially for the next year.

Over half of the respondents said that local authorities had conducted negotiations with them inefficiently. A third of charities with community care contracts reported they were in a better position, 17% reported being worse off. The rest saw no advantages over previous grant arrangements.

While 42% of charities said they were "poised for growth" in the new climate, 14% were "just surviving" and 44% were "feeling unsure" about the future. Less than half were optimistic about how the voluntary sector would cope with providing community care in the future.

KEYS OF THE DOOR

How time flies! Only last August LINK was reporting that the first turf had been cut for the joint housing project between Sheffield ASBAH and Sheffield Association for People with Cerebral Palsy and already Stothard Court has welcomed its first residents.

All nine bedsits are now taken, and "there is a buzz about the place", says Sheffield ASBAH. "All younger people together, with lots of coming and going - college, work, shopping, church and the local pub. Occasional trips to the snooker, cinema, or an evening of Trivial Pursuit for those who sign up for them... and they have only been there a month!"



New residents of Stothard Court- L-R (back): Jane Murphy, Philip Gibson (support co-ordinator), Philip Harrison; (front): Jackie Kelly, Patrick Robbins, Debbie, Jeremy Dean.

CROWN GLORY FOR BARRY

Shown on this issue's cover is Barry Hussey, from Birmingham, who won a silver medal at the World Disabled Bowls Championship in Australia.

Barry, aged 29, learned to play bowls seven years ago and has since risen to be one of the top players in the world of disabled sports. Until two years ago, he had to bowl from special areas because his wheelchair would have damaged the grass, but friends raised the money to equip him with a special wide-wheeled bowls buggy which he now uses to get about bowling greens.

Mr Hussey, who works at the Spina Bifida and Hydrocephalus Sheltered Workshop in Sparkhill, said: "I'm hoping now I might be able to get selection for the next Disabled Olympics in Atlanta, Georgia, in 1996."

Events

RADAR Workshops

In July, RADAR will be running the last two in a series of regional workshops on **Housing and Community Care** to examine the needs of disabled people. The venues are Chester (6 July) and Brighton (15 July).

Rachel Scott, RADAR, 25 Mortimer Street, London W1N 8AB. Tel: 071 637 5400.

Into Europe

ASBAH chairman Patrick Daunt will chair a two-day European conference at Enham Place vocational assessment and training centre in Hampshire at the end of June - as part of the celebrations to mark the 75th anniversary of the founding of the Enham Trust for the rehabilitation of disabled ex-servicemen.

The conference *Into Europe - New Perspectives for People with Disabilities* - will be held on 30 June and 1 July. Details: *Effective Technology Marketing Ltd, tel 0472 210707.*

Behind the wheel

The RAC is holding the 1993 RAC Response Disabled Driver of the Year Competition this summer. Six regional heats are scheduled in Wiltshire, London, Warwickshire, Durham, Lancashire and Scotland from mid July, to be followed by a final at Castle Donnington in Leicestershire on 13 September.

Contestants will be competing for the chance to win a £2500 holiday to the destination of their choice. Seven finalist runners-up will win short break holidays and all finalists will get their own RAC ET, an in-car Emergency Telephone with a direct line into the police and breakdown services. All contestants in the regional heats will win a year's membership of RAC Response, the specialist recovery service for disabled motorists.

RAC Response Disabled Driver of the Year Competition, c/o 36 Whiteladies Road, Clifton, Bristol BS8 2LG.

Making music for ASBAH

Tickets are now on sale for the concert to be held at the Corn Exchange Cambridge on 17 October.

ASBAH'S President Jeffrey Tate will conduct the English Chamber Orchestra in a concert of music by Mozart, Mendelssohn and Mahler, in the presence of our Patron, HRH The Duchess of Gloucester.

Box office tel: 0223 357851

New trio elected

Three more disabled members have joined ASBAH's national executive, as the association delivers its promise to involve more members with disabilities in the actual control of ASBAH.

Two of the three newcomers, Jon Burke and Terry Denyer, were nominated for the executive by the 'Your Voice in ASBAH' group - set up after national chairman Patrick Daunt launched a new era in consultation a year ago.

The new new arrival was Katrina Groundsell, a member of Essex ASBAH.

The trio bring the total number of members with disabilities now sitting on elected committees up to six.

The new consultative process is embodied in the 'Your Voice' group which has held three discussions since Mr Daunt chaired the large meeting which started it all in May 1992. Next meeting of 'Your Voice' will be at Peterborough on Saturday, 12 June.

Six members attended the last 'Your Voice' meeting on 17 April. These included new members Carole Armour, from Leicester, and Kevin Fetterplace, of Blackheath, South London.

They considered a variety of topics - besides naming members to fill the vacancies on executive. These included independent living issues and ASBAH's draft educational policy statement.

For more information on 'Your Voice' and dates of future meetings, please contact: Tony Britton, Publicity Manager, ASBAH House, 42 Park Road, Peterborough PE1 2UQ, tel 0733-555988.

Centre wants moral and physical lift!

Our South East regional centre in North London moved offices at the end of last year - without being in a position to give wheelchair-users complete run of the building.

Now, a £3,400 appeal has been launched to make amends. The money will be used to buy an inside lift so that all visitors have access to every part of the office.

"When we rented the office, there were no premises in the price range we could afford which gave us both a shop window at street level and an inside wheelchair lift", said regional co-ordinator Gina Broughton, whose office is at 123 East Barnet Road, New Barnet.

"As a result, we have a regional centre which is very easy to find and get into. But, because a small staircase separates the front office from the back rooms, it is very difficult for people with restricted mobility to get from the front to the private interview room, the kitchen or the toilet."

The regional centre - in a former specialist window shop - is at the sharp end of ASBAH's support and campaigning for 2,500 families throughout London and the South East.

"An office run by a campaigning disability organisation should be completely accessible to people with disabilities. That is why I'm giving priority to our need for an inside lift - over fundraising for office luxuries like a photocopier or a fax", added Gina.



Right on! Gina Broughton (right) and office secretary Denise Taylor strike out for a successful appeal.

Link Editor

This issue is the first produced by Jeanette Dixon (*pictured*), who has been appointed ASBAH's new editor. She has a wealth of experience in editing partworks and similar magazines, working most recently in the publications unit at PHAB.

She sees LINK as a powerful way not only to project ASBAH's news, views and policies but to help bind the ASBAH community together throughout England, Wales and Northern Ireland.

Please contact Jeanette on 0733-555988 if you have anything to contribute. She works part-time, so the best time to catch her is weekdays between 11am and 2.30pm.



SPINA BIFIDA OCCULTA and tethered spinal cords

Carys M. Bannister

Spina bifida occulta literally means a hidden split in the spine; hidden because the deformity of the spine and any associated abnormalities of the spinal cord and its nerve roots are covered by skin. The skin may be normal or it may have long coarse hairs growing from it; there may be a dimple in the skin or it may be blemished by a port wine stain. Sometimes there is a fatty lump in the tissues just beneath the skin. **Spina bifida occulta can affect any level of the spine but it is usually found in the lower part of the back.**

In the most minor form of spina bifida occulta the plates of bone which form the spinal arch fail to fuse completely. About one in four normal people find out by chance, after having their backs X-rayed for other reasons, that they have the condition. In this form of spina bifida occulta, which is a variation of normal, generally only one vertebra is affected, usually the one lying lowest in the small of the back. There are no associated abnormalities of the spinal cord or nerve roots and, therefore, there are no leg, bladder or bowel problems.

In other forms of spina bifida occulta the bodies of several of the vertebrae may be fused together giving rise to a back that may be slightly short and one that is often

Carys Bannister is consultant paediatric neurosurgeon at Booth Hall Children's Hospital in Manchester, and has previously written for LINK on the subject of the Dandy-Walker Syndrome.

stiff; sometimes the natural curves of the back are exaggerated, there may be an abnormal curvature of the spine or a bony prominence may be present in the midline of the back. The spinal canal at one level may have a bony peg or a fibrous band running across it and dividing it in two. Abnormal tissue, either fat or fibrous tissue, lying inside the spinal canal can cause it to be excessively wide.

All of these spinal deformities can be associated with abnormal development of the spinal nerve roots, and sometimes of the spinal cord as well. The spinal cord may be too long and instead of ending midway down the small of the back, runs almost to the end of it. The nerve roots arising from such a spinal cord travel in unusual directions before leaving the spinal canal. The spinal cord may be split in two by the bony peg or fibrous band mentioned above. The nerve roots arising from the lower end of the spinal cord may be enveloped in a mass of fatty or fibrous tissue. The spinal cord may be attached to the walls of the spinal canal by a fibrous cord. Sometimes a cyst, called a dermoid, lies amongst the nerve roots, and it may be connected by a fibrous tract to a

dimple in the skin. Almost all of these abnormalities can fix the spinal cord to the spinal canal and cause tethering of the spinal cord.

Apart from abnormalities of the spinal cord and nerve roots at the level of the bony deformity, there may also be mal development of the spinal cord at a higher level. Normally there is only a potential space in the centre of the spinal cord but it can expand and become filled with fluid. This may cause no trouble at all but if it continues to expand it can lead to loss of power, feeling and coordination of the movements of the legs and even the arms in some cases.

Because the nerve roots at the level of the abnormalities run to the legs, bladder and bowel, their function may be affected. In particular, development of the calf muscles may be poor, causing thinning of the legs below the knees; there may be loss of feeling in the calves and feet; and because there may be imbalance of the power of the different muscle groups, clubbing of the feet and clawing of the toes may occur. It is not uncommon for one leg to be more affected than the other. Bladder and bowel function is less often disturbed, but bladder and

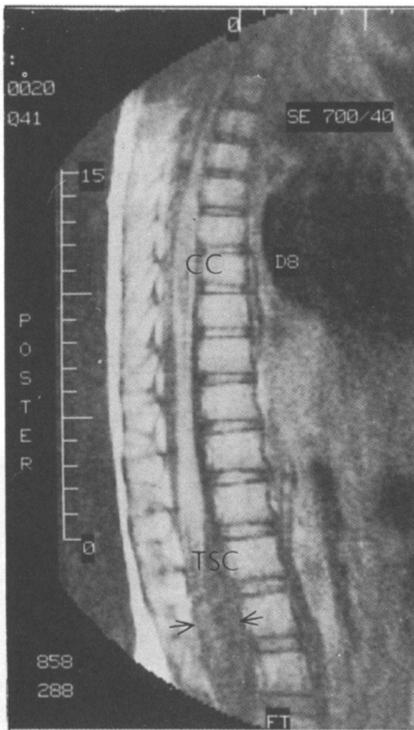


Figure 1

A Magnetic Resonance scan of a child with tethering of the spinal cord (TSC) in a widened spinal canal (arrows). There is also widening of the canal (CC) in the centre of the spinal cord at a higher level.

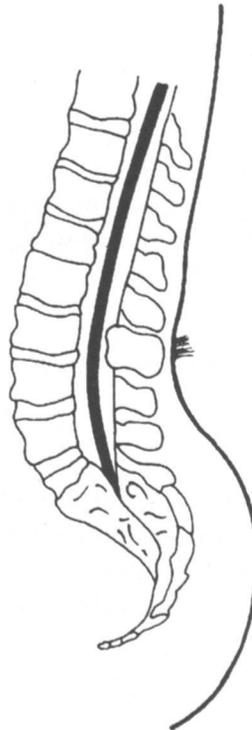


Figure 2

Spina bifida occulta is usually found in the lower part of the back. The deformity is covered by skin, which may be dimpled or have coarse hairs growing from it.

bowel incontinence or retention of urine and constipation can occur.

Babies at birth are suspected of having spina bifida occulta if they have one or more of the skin abnormalities described above, and if the shape of the back is abnormal. It is not usually possible to detect the full extent of the spinal cord and nerve root problems at first, it is only as the child gets older that thinning of one or both calves may become apparent, and it is not until the child is old enough to co-operate in a detailed examination that loss of skin sensation in the calves and the feet can be discovered. Likewise, it may not be appreciated that the child has a problem with bladder and bowel control until he or she is old enough to be potty trained.

Plain X-rays of the back will generally show the bony deformity, but in order to see the abnormalities lying within the

spinal canal some other form of investigation has to be carried out. By far and away the most helpful is a Magnetic Resonance (MR) scan. This can be used to measure the whole length of the spinal cord, as well as the nerve roots and any soft tissue swellings lying within the spinal canal at the level of the bony abnormality (Fig.1). Scans with X-rays, CT scans, are also helpful but do not give as much information as MR scans and cannot be used to examine the whole length of the spinal cord because of the large amount of radiation needed to do this. Injection of dye into the spinal canal, a myelogram, is only performed these days in special circumstances.

It has to be emphasised that the bony, spinal cord and nerve root abnormalities of spina bifida occulta are all due to a mal development occurring early in pregnancy which cannot be

corrected by operation. The thinning of the calves, loss of feeling in the lower limbs and poor control of bladder and bowel function are therefore permanent disabilities requiring long-term management. This does not mean that children with spina bifida occulta cannot be helped by surgery. The fatty and fibrous tissue in the spinal canal sometimes compresses the nerve roots causing them to stop functioning or to give rise to pain. It is also believed that growth can cause tethered nerve roots and the spinal cord to become taut, and may be the cause of weakness and loss of feeling in the legs and loss of bladder and bowel control developing for the first time in the older child. It has been suggested in the past that it might occur at puberty but there is no evidence to support this. A dermoid cyst in the spinal canal can gradually enlarge and cause pressure on the spinal cord and the nerve roots, or if it is connected to a skin dimple by a fibrous tract, it can become infected. For these reasons a child with spina bifida occulta needs to be examined at regular intervals in a clinic to look out for signs of deterioration in the power and feeling in the legs and in bladder and bowel function. If these are detected an operation may be needed to free the spinal cord and nerve roots from whatever is tethering them or causing compression. This may mean that fat and fibrous tissue has to be taken away, a peg or fibrous band running through the spinal cord has to be removed, or a dermoid cyst cut out.

A child who is not deteriorating may need an operation to correct a club foot, or to improve the balance of power of weak leg muscle by transferring their tendons so that they exert their pull on different parts of the foot or ankle. Because skin without feeling is easily damaged and slow to heal, constant thought needs to be given to skin protection to avoid damage by pressure. If

bladder and bowel function is affected, management is along the same lines as that used for children with meningomyeloceles, and includes regular checks for water infections, as well as repeated investigations to ensure that the kidneys are not being damaged. Intermittent catheterisation may be

needed and bowel management may require the use of suppositories or mini enemas.

Spina bifida occulta is therefore a condition which can vary from one that is insignificant to one that has long standing serious consequences affecting the legs,

bladder and bowel function. In spite of having some features in common with meningomyeloceles, spina bifida occulta is an unrelated condition, for instance, it is not associated with hydrocephalus, and it has an entirely separate pattern of inheritance.

Poetry Anthology

POETS, this is your chance to get into print - thanks to Peterborough writer Ron Lucas, who once a year publishes a collection of other people's verse for ASBAH.

Ron is inviting LINK readers to get a poem off to him before October this year, and it will be considered for inclusion in his next anthology, which will be out early next year.

"The anthology will be open to unknown as well as to famous writers. I want people to send me their poems - anything from half a dozen lines to a maximum of 30 so to get them on one page," said 44-year-old Ron.

His latest anthology *All Together Now* contains work by 168 writers, including top authors Benjamin Zephaniah and Pam Ayres. Profits from it totalling £400 so far have already been handed over to ASBAH.

"The only thing I insist on is quality. The poems must be up to the writer's highest standard before they can be considered," he added.

All Together Now, beautifully bound and printed by Peterborough-based Poetry in Motion Writers, is a multi-talented celebration of the power of words to excite, inspire and just make readers laugh. It harks back for its title to The Beatles and Ron's native Merseyside.

Unknown writers included are Martin Thorn, who has penned a poem about his disabled daughter Gilly, and Paul Wootton, a fundraising manager at ASBAH House.

Ron, who is dyslexic, refuses to let his own disability interfere with his joy in writing - even though it sometimes means other people have to tidy up his spellings.

Now you can send one of your poems off for appraisal, and perhaps enjoy the sensation of seeing your own work in print.

Send the poem, by October, to Ron Lucas, 28 Oxclose, Bretton, Peterborough, with of course your name, address and - if it's relevant - your age.



Ron Lucas (centre) reads from his latest anthology, with fundraisers Paul Wootton and Deirdre Pawsey looking on.

Better clinic deal in Northern Ireland ?

A move to give children with spina bifida in Northern Ireland a better orthopaedic deal has been welcomed by ASBAH - after last summer's wholesale cancellations of appointments delayed treatment of many members.

The Royal Belfast Hospital for Sick Children has announced that - from 1 August - it will have the funds to appoint a senior house officer to assist consultant Mr Kerr Graham, who each summer is inundated with accident work.

Hospital managers gave the news to Mrs Margaret Reid, chairman of Northern Ireland ASBAH, and Mrs Meta Harvey, our regional coordinator, at a meeting in mid-May.

The meeting was requested by ASBAH amid growing fears that the hospital was about to announce a new round of cancellations of spina bifida clinic appointments this summer.

ASBAH has been monitoring the deteriorating situation since last year.

After the meeting with Mr William McKee, chief executive of the NHS Trust involved, and Mr Steven Brown, the clinical director, Mrs Harvey said:

"We were told that, as from 1 August, there will be funding for a senior house officer in orthopaedics who will deal with the bulk of the trauma and emergency work.

"We hope the appointment of this

extra member of staff will follow quickly. It will result in the consultant in charge having more time to deal with spina bifida children. These children require frequent surgery if they are to keep as mobile as possible," she said.

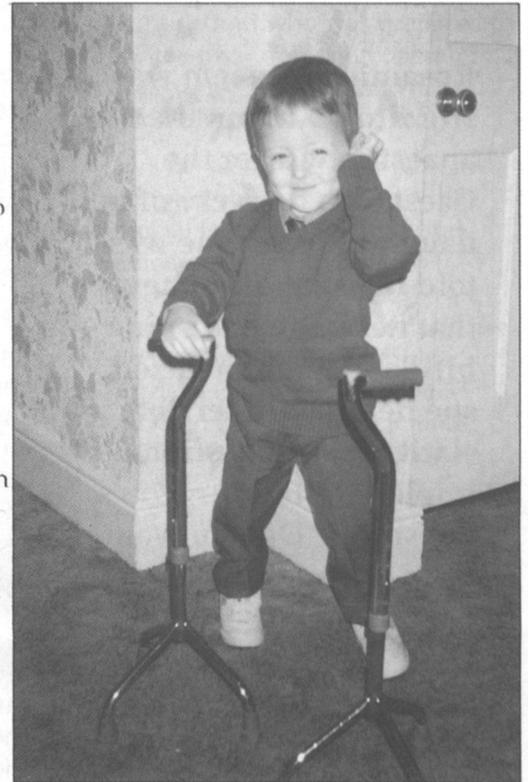
"Last year, spina bifida children were pushed to the back of the queue for treatment - a situation which we said at the time was disgraceful. Hundreds rely on surgery at RBHSC for a good outlook to their future."

Mrs Pauline Clarke, of Derry, whose six-year-old son Brian has spina bifida, hydrocephalus and osteomyelitis, commented: "Mr Kerr is a great man, a brilliant man, but he has just not got the time to do all the work himself.

"I met him in January when he told me that he has just had enough of the situation in Northern Ireland, and was considering job offers from three other places. It's so sad: I must be the only parent in my group who, because I have battled for it, has managed to keep a clinic appointment for my son.

"A friend of mine has a son who had an operation a year ago but whose follow-up treatment was cancelled. It's put him back months."

Orthopaedic surgery for children with spina bifida has been concentrated on the RBHSC - where it has been tacked on to a Tuesday afternoon fracture clinic run by Mr Graham.



Brian Clarke - one of the children in need of attention in the orthopaedic clinic.

His accident and emergency workloads have increased enormously since he took over the post six years ago. The clinic's busiest time is in the summer when children injure themselves while playing out of doors.

"We need a standing arrangement that secures in one clinic all the medical and surgical attention required by children with spina bifida", added Mrs Harvey.

"We do not need a repeat of last year when parents did not know from one month to the next when their children would receive attention."

Tony Britton

● Letters, page 26

A parent, in sickness and in health

Rosamine Hayeem was still drowsy from the anaesthetic after the Caesarean delivery of her daughter when she was told the shattering news that her baby had spina bifida. Although dazed, she heard with terrible clarity the suggestion implicit in the surgeon's question: "Do you want us to do anything about her nor not?"

Medically, the baby's life was in the doctor's skilled hands, but from that first moment the decision to save the child belonged to the mother. By telling the doctor to operate, Rosamine Hayeem knew she had elected to fight for Judith, even if it meant flying in the face of medical opinion.

"They told me she would deteriorate. That she could easily be just a vegetable," remembers Mrs Hayeem. Her daughter Judith, 22, now has a BA in psychology and is completing her MSc in experimental psychology at London University. "Through Judith I learnt that as a parent you can become forced to challenge the medical establishment. That no doctor, no matter how dedicated, can fight for a sick child's health as a parent can."

March saw the release of *Lorenzo's Oil*, a film about two parents faced with the horror of their son's impending death from a rare condition called

Is understanding your child's illness the best way to protect it? Carmel Fitzsimons on challenging medical opinion.

adrenoleukodystrophy. Doctors told Augusto and Michaela Odone that there was no cure for their son, Lorenzo.

The Odones had no medical expertise but they felt the battle for their son's life could not be left to the medical establishment alone. Combining work, caring for the boy and studying in medical libraries from dawn to dusk required an almost superhuman effort but the Odone parents finally made a breakthrough and Lorenzo began to recover. In recognition of his work, Lorenzo's father was awarded an honorary medical degree. The oil he discovered as part of the cure has saved hundreds of boys but it took lion-hearted parental love to find it, not qualifications in biochemistry.

The Odone story is an exceptional one, but it illustrates one of the difficult choices facing parents of sick children. Many, hearing their child is sick - be it with a life threatening illness or a more common condition such as eczema - become paralysed with anxiety. They do not ask too many questions - and they gratefully accept any medicine, any hope. Others feel they have to become experts in their child's condition if they are going to be able to best protect their offspring.

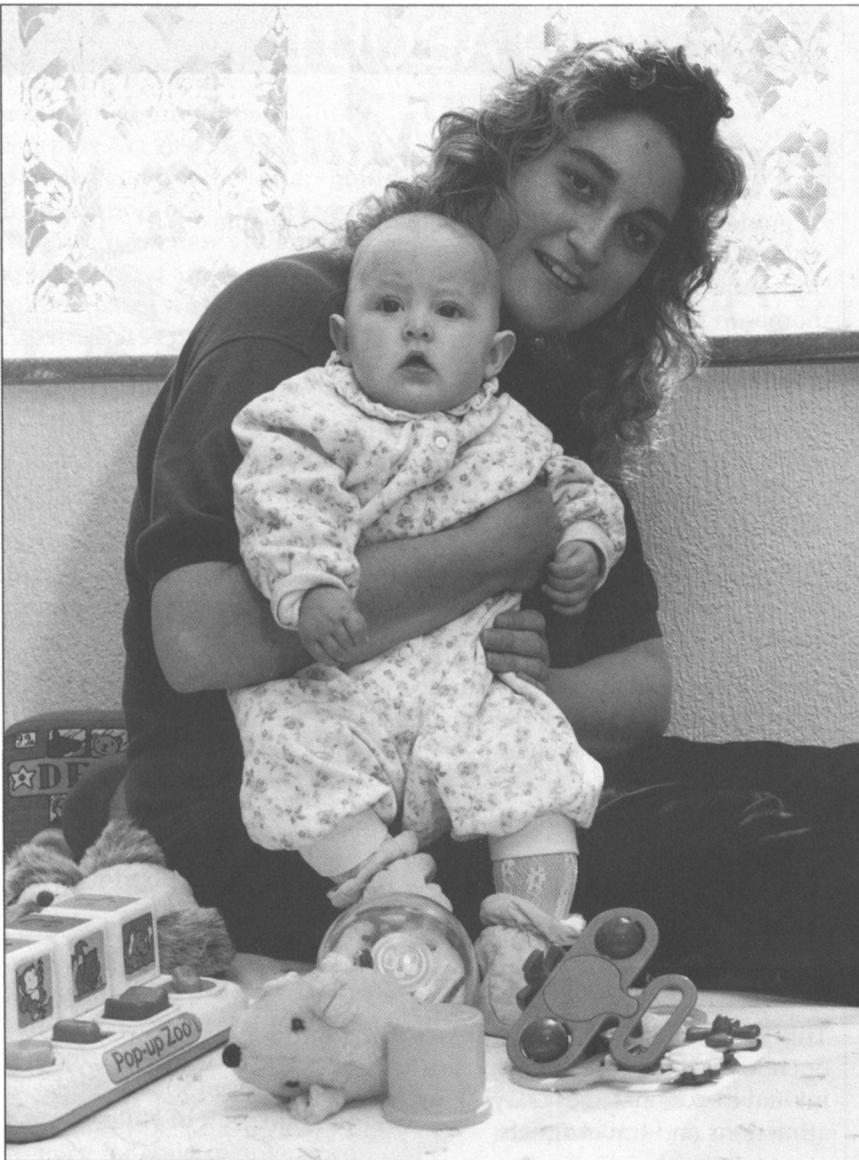
Rosamine Hayeem is of the second school. "I think parents have to be prepared to do their own homework. People I met in hospitals would often ask me why

I did not just listen to what the surgeons said, but I suppose it's a matter of personality with me. There are mothers who are afraid and intimidated by doctors but I could not leave my daughter's care to someone else."

Spina bifida is a condition that occurs in the foetus early in pregnancy, affecting the neural tube which develops into the spine and brain. When the child is born, surgeons have to close up the lower section of the spinal cord which has been left exposed, but there is usually paralysis below the fault. The condition is often accompanied by hydrocephalus, a swelling of the head caused because the excess spinal fluid bathing the brain fails to drain off quickly enough. Hydrocephalus can be effectively treated by inserting a valve, called a shunt, into the cavities of the brain.

The spina bifida affecting Abe and Rosamine Hayeem's daughter Judith was relatively mild, but it was the hydrocephalus that became the battleground. Within months of the first shunt being positioned, the Hayeems realised that it had started to block up.

They contacted the Association for Spina Bifida and Hydrocephalus (ASBAH) and read everything they could on the mechanics of shunt surgery. In one year alone Judith had to go to hospital 18 times because the shunt had blocked. "I knew she was suffering tremendous pain, but if pressure was allowed to build up



Carrie Nesbitt-Larking with her daughter Mary.

on the brain it could end in blindness, spasticity, mental handicap," said Mrs Hayeem.

Judith developed "slit ventricle syndrome", where the cavities which hold the shunt become too narrow. Mrs Hayeem became determined that there had to be some sort of engineering step that could be taken to control Judith's condition and put an end to the constant surgery. She raised money to go to America to discover the state of the art there. She spent hours ringing hospitals, asking what was the latest technology they could offer for hydrocephalus sufferers, and was finally put in touch with the Hospital for Sick Children in Toronto.

Mrs Hayeem took Judith to Toronto twice, where new shunts were implanted. She learnt about a new technique called sub-temporal decompression where doctors made an opening in the skull which allows the brain to expand and widens the slit ventricles enough for the shunt to drain the fluid. But when, after yet another horrifying shunt blockage incident, she suggested the technique to the eminent surgeon at a reputable English hospital, she was treated with contempt.

"The surgeon refused to see that Judith's condition was becoming critical. He wrote to my doctor saying I was neurotic and that Judith's headaches were psychological. I could see from the

scans that Judith's ventricles were blown wide open and eventually I took the only course open and flew her back to Toronto where they operated immediately, astounded that no one apart from her parents had recognised the danger she was in."

Finally, in 1985 the Hayeems found a surgeon who had trained in Toronto and who was prepared to try the decompression operation. It was a success and Judith has not had a shunt blockage since.

Mrs Hayeem, a teacher with two adopted children, believes the crucial factor in the successful management of Judith's hydrocephalus was that she and her husband were not intimidated by the complexity of Judith's medical condition. "We found in Toronto there was much more information available - doctors would give parents papers they had written on the subject. Here surgeons want to preserve their mystique, and if we had not been prepared to challenge them I do not think Judith would have the quality of life she has today."

Carrie Nesbitt-Larking's five-month-old daughter, Mary, also suffers from hydrocephalus but she is happy with the medical help her child has received. "I know I am at the mercy of the neurosurgeons but I feel lucky that I live close enough to Great Ormond Street Hospital to benefit from the expertise of the top doctors in the country. There is no home remedy like oil of evening primrose that could benefit Mary, no simple treatment I could offer her. I have to put my trust in the experts."

Mary's hydrocephalus was revealed in a routine scan at 39 weeks of pregnancy and within three hours the baby was delivered by emergency Caesarian section. Within 48 hours, Mary had her first operation to insert a shunt.

Over the next few months there were setbacks, including a horrendous episode when the

shunt burst. Now Mary's condition has stabilised but Carrie, a nurse, is the first to admit that she has been reluctant to find out too much about the condition. "I wanted to know if there was a support group for the condition. My sister discovered ASBAH but it took me three weeks to feel ready to phone them. It was as if I was not ready to confirm that my daughter was hydrocephalic."

She has thought hard about why she has not chosen to educate herself about her daughter's condition. "If this was my niece, I would be reading about the physiology till it was coming out of my ears. My sister knows the anatomy of the brain backwards since this has happened. Because we are talking about my daughter, I feel that at present I only have a limited amount of questions I want to ask. I feel that I would have to detach myself from Mary in order to go and study the brain. I am happy to accept that the doctors know best."

According to Tony Britton of ASBAH, there is no right way to deal with the news that your child has a serious condition such as spina bifida or hydrocephalus. He is convinced, however, that contacting a support group such as ASBAH is the important first step.

"Most parents have to spend a period grieving for the healthy baby they have not had, and that can take months. We feel that by getting in touch with us they are already beginning the process of acquiring the knowledge which will help them gain control over their situation.

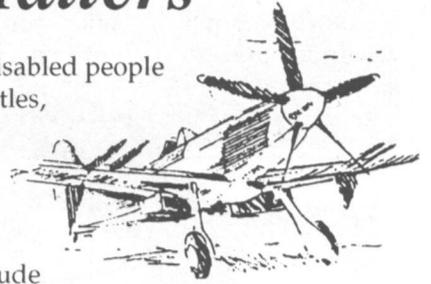
"We have trained fieldworkers who can work alongside families ensuring they get the best treatment. We do not impose any judgements about the lengths to which they should go to help their child. But, when the need arises, we are there to fight for families."

This article first appeared in 'The Independent on Sunday' Review, 28 March 1993. ■ Letters page 26

OUT AND ABOUT

Military Matters

A guide has been published to help disabled people enjoy a fascinating collection of 33 castles, museums, warships and stately homes in Hampshire, Dorset and the Isle of Wight.



Known collectively as the *Defence of the Realm* collection, the warships include *HMS Victory* and *HMS Warrior* and the *Mary Rose* in Portsmouth, Aldershot Military Museum and the D-Day Museum.

All the sites have been inspected by the Holiday Care Service - a charity offering holiday information and support and all people with special needs.

Many but not all are wheelchair-accessible. Some interpret their exhibits through audio-tapes or offer touch facilities for blind and partially-sighted people. Some have specially-trained staff to welcome visitors with special needs.

The guide and copies of a colour brochure from: Defence of the Realm, Ferry Gardens, South Street, Gosport PO12 1AEP, tel 0705 504332.

Nominations, please

This year's Holiday Care Awards is being thrown open to disabled tourists - who are being invited to nominate best stays, tourist attractions and travel agents.



And the winning hotels and tourist attractions are being offered free supply and installation of automatic door-openers or a pair of doors by Besam, the Sunbury-on-Thames specialists in automatic door-operating systems.

Nomination forms from: Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW, tel 0293 774535.

Northern nights

Self-catering holiday homes and activity holidays in the heart of the Kielder Forest, Northumberland, are being offered by the Calvert Trust - specialists in holidays for disabled people, their family and friends.



Single rooms with 24-hour care are also available for holiday breaks between October and June, and reservations must be made in advance.

Activities close to hand for the more vigorous include sailing and canoeing on Kielder Water, climbing, abseiling, horse-riding, driving and archery.

Calvert Trust Kielder, Hexham, Northumberland NE48 1BS, tel 0434 250232.

April 1993 saw the introduction of a new system of Child Support. The main principle, as established under the Child Support Act 1991, is that absent parents, and not the state, should help support one-parent families. To this end, a new system to assess, collect and enforce child maintenance was introduced from April 5th, 1993.

The newly created Child Support Agency has been created to take over these functions from the courts and, in the case of parents on benefit, from the Benefits Agency. The Child Support Agency, whose functions will be phased in gradually over a period of four years, will take over responsibility for assessing maintenance and will have powers to trace absent parents, investigate their means, collect payments and take enforcement action where necessary.

● Parents on benefits

From April 1993 parents "with care" (with whom the child is living and who provide day to day care), who are in receipt of Income Support, Family Credit or Disability Working Allowance will have to apply to the Child Support Agency for child maintenance. Parents with care already in receipt of any of these benefits at the time of the change over will be transferred to the Child Support Agency in stages between April 1993 and 1996.

● Parents not on benefits

People not in receipt of these benefits and who have an existing maintenance agreement (either voluntary or by court order) will be taken over in alphabetical order after April 1996.

Parents who do not already have a court order, and who want to settle child maintenance, will have to go to the Child Support Agency and will be charged a fee.

By 1997 any parent, whether on benefit or not, wishing to obtain a formal agreement will have to go

Child Support

THE APRIL CHANGES

through the Child Support Agency for maintenance.

● The Role of the Courts

The Courts will retain responsibility for all related matters including access, paternity disputes and property issues. However, the courts will still deal with some child maintenance issues, such as requests for additional maintenance, for example, to meet extra costs for children with disabilities.

● Who is liable to pay maintenance

Liability to pay applies to all parents living apart whether they are divorced or separated from the other parent or have never lived with them. This includes absent parents on Income Support who will usually have the minimum amount of maintenance (£2.20 per week) automatically deducted from their benefit.

Liability continues until the child reaches 16 (or 19 if still in full-time education) even if either parent remarries. Liability ceases when a child is adopted and liability does not apply to parents living abroad.

● Who is exempt from the minimum

If the maintenance assessment is for less than £2.20, the absent parent does not have to pay that minimum if they are getting

*Sickness Benefit, Statutory Sick Pay, Maternity Allowance, Statutory Maternity Pay, Invalidity Benefit or Severe Disablement Benefit.

*Attendance Allowance, Disability Living Allowance, Disability Working Allowance, an industrial disablement benefit or a war disablement benefit.

*Invalid Care Allowance.

● Tracking the absent parent

A parent with care of a child, who is on Income Support, Family Credit or Disability Working Allowance or someone claiming these on their behalf is required to authorise the Child Support Agency to seek maintenance from the absent parent.

Parents will not be required to authorise collection from an absent parent if the agency is satisfied that there would be a "risk of her, or any child living with her, suffering undue harm or distress" as a result of her co-operation.

● Penalty for non-cooperation

If a parent refuses to co-operate a reduced benefit penalty may be applied. The penalty will mean a deduction from benefit of 20% of the adult personal allowance of Income Support for the first six months, followed by a deduction of 10% for the following 12 months.

A parent with the care of the children can appeal against the decision to apply a deduction but the deduction will be made until the appeal is heard.

There is no discretion to apply a lower penalty or shorter penalty even if a person or member of their household is sick or disabled.

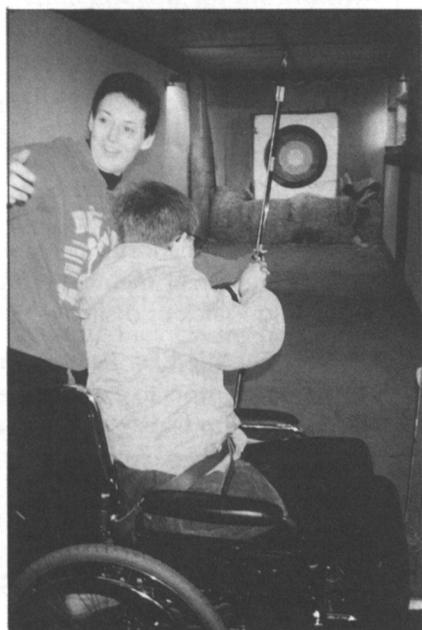
A booklet entitled *For Parents who live apart* attempts to explain the complex methods used to calculate the maintenance payable. It also gives details of the amount that absent parents may be expected to pay. A booklet can be collected free from Post Offices, CABs, DSS offices etc.

Sport for all

The aims of a PE programme for pupils with spina bifida and hydrocephalus will be very similar to those of an able-bodied child, with emphasis on the following five points.

1. To encourage movement and thus promote fitness and health.
2. To promote movement as enjoyable and interesting and thus *motivate* the child towards further activity inside and outside school.
3. Through physical education, to foster self-confidence, independence and social contact.
4. To develop strengths in each child according to his or her individual needs, enabling the child to compensate for some of the limitations presented by the disability.
5. To develop skills which, hopefully, will benefit the child in a recreational context and also functionally through competence in daily living skills.

Those involved in the physical



The process of integration for a pupil with spina bifida and/or hydrocephalus into the mainstream physical education programme is not an easy one but with positive attitudes and determination much can be achieved. In this article, Chris Russell-Vick, a teacher at Chailey Heritage School in Sussex, looks at the PE curriculum and considers how the pupil with special needs can be included.

education programme should be aware of several factors. The sensation in the lower limbs and lower half of the trunk may be affected and this will, of course, vary with each child. A leg injury may cause no pain, therefore care must be taken.

Where sensation in the lower limbs is affected, children can forget that their legs exist. As a result they tend to move about dragging their legs, oblivious of the damage they are doing. The PE lesson can provide an excellent opportunity to teach these children to manoeuvre their bodies safely and effectively.

Physical activity can cause incontinence appliances to come adrift. An awareness of this means the incident can be avoided or dealt with with the minimum of fuss. Bear in mind that some pupils can have a skilful knack of covering up a problem and giving an impression of confidence and having understood a set task. Some are not aware of their body in relation to space, nor do they see it as others see it. Make sure, then, that all instructions are clearly understood, eg does the child appreciate the meaning of "line up behind me!"; does he *really* know which way he is supposed to be shooting? Remember, also, that a child can be strong in upper body but have difficulty with manual dexterity,

hand-eye coordination and fine motor control.

● Adapting physical activities

The main objectives in adaptation are to allow children to achieve success while taking part and to gain enjoyment from maximum participation. There are many ways in which we can simplify the level of performance necessary for this.

Simplification of motor problems

- ★ Substitute walking or wheeling for running parts of a vigorous game.
- ★ Substitute lighter apparatus to improve control over implements. Light plastic bats are much easier to handle and can be managed in one hand.
- ★ Allow able-bodied runners to run for or to push wheelchair players.
- ★ Larger balls can be introduced to simplify catching and striking techniques.
- ★ The size of the playing area can be made smaller, thereby reducing the amount of gross motor activity proportionately.
- ★ Increase the number of players in a team to reduce the amount of space for which each player is responsible.
- ★ Modify starting positions to achieve a stable, more balanced

Look at their ability, not disability

An integrated PE programme allows children to gain enjoyment and achieve success, as these photos of pupils at Chailey Heritage and their friends from Laughton School demonstrate.



position from which certain skilled actions can be performed.

- ★ Decrease the length of pitch or distance from targets in aiming or throwing activities.
- ★ Restrict certain players to a specific position on court according to their freedom of movement.
- ★ In net games the height of the net considerably affects the speed of play. A high net produces a slower game by forcing a higher and slower ball flight. The players must, of course, have good enough arm control to clear the net. Use of a lower net speeds up the game but makes throwing and batting easier.
- ★ The substitution of beanbags and foam decreases the distance the implement travels and reduces the play area accordingly.
- ★ Overinflated beach balls simplify batting procedure in net games.

- ★ Substitution of large bean bags for balls simplifies the grasp and release problems.

- ★ Use a chute for severely disabled players in bowling activities.

Simplification of perceptual problems

- ★ Use of multi-coloured play balls helps to reduce visuo-motor problems.

- ★ Ball flight must be modified to suit the child with spatial problems and the tempo of the game must be reduced to match the slower perceptual-motor responses of the child. The ball service in a game may be reduced in difficulty and progressively graded as skill improves: first rolled, then bounced, then thrown underhand. The size of the ball affects visual tracking ability; larger balls are easier to follow in flight.

- ★ The degree of bounce may be reduced by using foam and low-bounce balls.

- ★ Beach balls tend to float in the air and thus slow down the responses needed from players. Balloons may be substituted in net games, but care must be taken in case of a loud burst!

- ★ Simplify and reduce the number of decisions a child has to make within a game.

- ★ Adapt the starting position of the child and the flight of the ball to ensure that both the hands and

the ball are always within the visual field.

Simplification of the playing environment

- ★ Rule changes may be made to simplify performance in any game so long as the game remains recognisable, particularly to older players. The rules controlling performance by certain individual players within a game may be slightly different to compensate for varying degrees of disability.

- a) Different types of service in striking games according to ability - rolled, bounced, thrown etc.

- b) "Safe ball" rule - in passing games, defending players may not infringe within two metres of a disabled player or overguard. Only a team mate may take the ball from him.

- c) Shorten the duration of a game by reducing the period of time or total of points necessary for a win.

- d) In volleyball and other net games, some players may catch the ball while the more able must bat or strike.

- e) Prevent the more able players dominating play totally by restricting their role. The "no-return-pass" rule in invasion games creates greater opportunities for the less able to take an active part.

- ★ During group or team games, select children for playing positions according to their movement potential. The role of the goalkeeper is obvious but, in general terms, in invasion games the more disabled players should either play in defence or as attackers in front of goal, with the



more mobile players acting as
midfield fetchers and carriers.

Reduce the fatigue factor in certain
cases where necessary by:

- a) shortening the game period;
- b) allowing freedom of player
substitution on a regular basis;
- c) switching the role of tired
players to that of referee or
linesman for a rest period;
- d) substituting cooperative
practice for the competitive game
situation;
- e) reducing the tempo of activity in
several of the ways listed above;
- f) reducing body contact situations
by introducing "no-running" and
"no-tackling" rules in team
passing games.



*Didn't we do well! Proud pupils after
completing a mini - marathon (above);
and a young athlete on course in the
60m dash (right).*



**There are many physical activities which
can be enjoyed by children with special
needs when straightforward adaptations
are applied:**

ATHLETICS
SWIMMING
ARCHERY
CARPET BOLSTER BOWLS
TABLE TENNIS
VOLLEY BALL
TARGET THROW
PRECISION THROW
WHEELCHAIR PROFICIENCY
SKILLS
OUTDOOR PURSUITS
WHEELCHAIR SLALOM
OBSTACLE COURSES
CIRCUIT TRAINING
RELAYS
DARTS/POOL
SKITTLES
DANCE
MUSIC & MOVEMENT

ATHLETICS

A wide range of activities can be selected. For
those pupils who would have difficulty
competing with the rest of the group in track
events, ie running, the following adaptations
could be made.

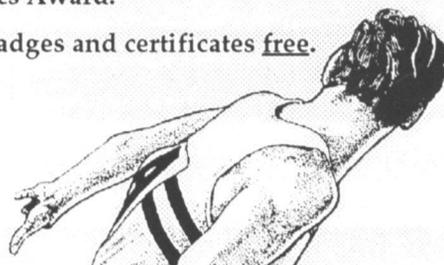
1. The individual times the event and tries to
improve on his or her own time, keeping a record
chart.
2. All the class group is timed over a set distance
using a wheelchair.
3. The pupil in the wheelchair can race the others
but with a shorter distance to finish in.
4. Develop track events for the wheelchair user, eg
wheelchair slalom.

Two very good award schemes that are suitable
for the whole group whilst giving the child with
spina bifida and/or hydrocephalus good access
are:

Five Star Athletics Scheme - which has an adapted
score chart for physically disabled athletes

IBM Athletics Award.

Both offer badges and certificates free.



On the road at last!

In April 1992, I visited a mobility exhibition to gain more information about powered wheelchairs and to find out from various car dealers what help I could obtain from Motability with regard to grants available from them towards the deposit on a new car.

I already leased a Motability car from them but was still able to work in 1989 when I obtained it. At that time, I was able to afford the deposit and the deposits were two or three times less than they are now. How times change! I found myself in need of assistance.

It transpired that Vauxhall were able to offer the best 'deal' with regard to the cheapest deposits on their cars so I visited their showroom.

Initially I would have liked an Astra because of its safety features. But, back in April, they had no plans for making automatics - so the next model to aim for was a Cavalier.

As plans were afoot to

fund raise for a Cheetah powered chair, it seemed like a reasonable idea to go for the Cavalier hatchback to make transportation of the chair easier too. All very simple and straightforward. The necessary forms were completed including a grant application form to Motability. The salesperson could give me no idea of the amount Motability would award but suggested that I state an amount which I would contribute towards the deposit, which at the time was £1,335. I offered £250 towards the deposit and said that I would pay for the adaptations to the car which were another £250. Nothing ventured, nothing gained, I suppose!

On 9 July, I received my first letter from Motability with a 'means test' form for me to complete. This was returned the following day.

On 27 July, I had my first telephone conversation with Motability. Their representative asked for details of the dimensions of the powered chair which I was happy to give. I attempted to explain that the Cheetah is no

ordinary fold-away chair but it

was obvious that she didn't quite grasp what was meant. Neither did she seem to understand why I should need an automatic car or why having power-assisted steering should be of help to me.

It seemed that Motability have very little visual contact with people with disabilities and little appreciation of some of the finer points of basic independence. Perhaps that is a little harsh - perhaps it was only this one person who had little contact with the disabled public!

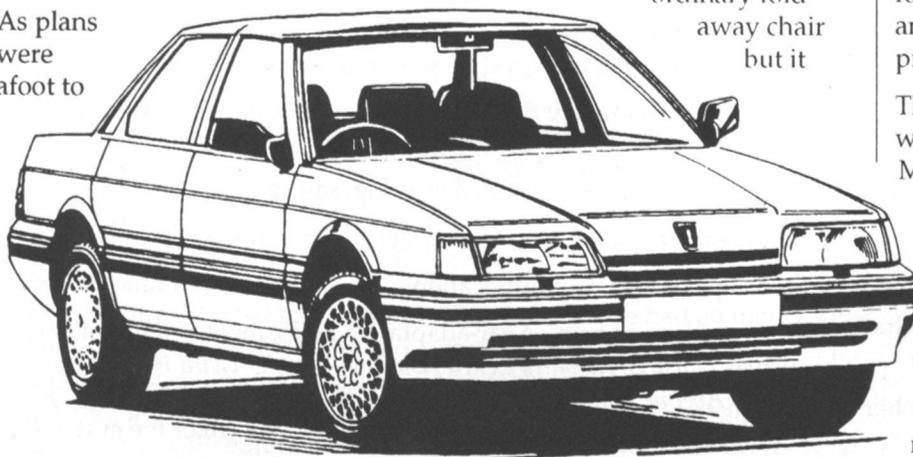
I then received a 'request' to try a Peugeot 205 and a Renault Clio as the Cavaliers were no longer available! I checked with the Vauxhall dealer who said there would be no problem in getting a Cavalier before arranging to see the Peugeot and the Renault.

Both cars were, as suspected, a little too small to accommodate myself, my wheelchair and the Cheetah. So I submitted my findings by telephone to Motability.

In the meantime, the fund raising for the Cheetah started in earnest and time was moving on when the present lease would expire.

Then came a letter in November with the suggestion that I repay Motability £1,440.

Feeling I needed an 'advocate' to phone Motability on my behalf, I asked my sister to contact them. She is a section supervisor at the DSS and obtained permission to make the call. She discovered my file was misplaced and then the person



dealing with my case was not available. So my sister asked to speak to one of their section supervisors. It was then she discovered that Motability had based their 'suggestion' on my receiving Attendance Allowance and that they classed it as income. My sister was definitely the wrong person to say such a thing to!

She obtained the name of a 'senior person' to whom I could write.

This I did on 6 November, and received an apology for the suggestion that part of their grant should be repaid. The manager agreed that this suggestion was outside current policy.

I was fortunate in the way things turned out. In February, I collected my new car. . . three months late but well worth the wait! It is not the Cavalier originally agreed; instead, for my £250 deposit, I

have a Cavalier 1.8i Envoy with power-assisted steering, five-door hatchback. It is a superb car and I am delighted with it.

Motability will no doubt continue to award their 'charitable repayable grants' but they can - and should - be questioned. It did make a pleasant change to ask them to justify their actions.

Sandra Wheatley

THE north of England was almost unoccupied fieldwork territory before Sandra Wheatley started work for ASBAH in 1984. She started with a huge patch covering Northumberland, Durham and Cumbria - from the Scottish border to Yorkshire.

The work quickly piled up, particularly after Sandra won the confidence of staff running the spina bifida clinic in Newcastle. She soon had over 500 families on her books.

It took longer to persuade local social services departments to fulfil their obligations to their clients with spina bifida and/or hydrocephalus. But, after a lot of stirring including a three-page special report in LINK on the plight of families in the North, their procedures were tightened up.

Three years after joining ASBAH, doctors confirmed that Sandra had multiple sclerosis. She carried on in post without complaining until April 1990.

Today, she lives in Woodham Village just outside Newton Aycliffe, Co Durham, where she has a bungalow and many friends.

"I thoroughly enjoy my life, although there are limits to what I can do. I would never have dreamed that I would have to rely on other people so much. Thankfully, their attitude is that it's no big deal," said Sandra.

Staff at the local DSS, where her sister is a section supervisor,

raised £4,500 in four months so that Sandra could have her powered Cheetah wheelchair. This means that she can continue to keep mobile and enjoy the company of friends out of doors.

Her Cavalier 1.8i Escort - big enough to carry both her lightweight wheelchair and the Cheetah - is another pleasure.

"I had a good time with ASBAH. Teresa, the fieldworker manager, still keeps in touch and so does Julie from Yorkshire. . . it's rather nice."



MOTABILITY - SPEEDING YOUR APPLICATION

There is currently a six-month waiting list for the Motability scheme. Obviously, anything you can do to hurry things along is worth the effort.

- * Be specific about your requirements. Point out that you've already tried a variety of makes and models and you know what suits you.
- * Let them know the type of wheelchair, ie rigid-framed, folding or electric
- * If you need power-assisted steering, say so
- * When writing or telephoning, get a name! It makes it easier to
- * Keep chasing your application!
- * Consider arranging a car-adaptation assessment at a mobility centre such as *Banstead Mobility Centre, Damson Way, Orchard Hill, Queen Mary's Avenue, Carshalton, Surrey SM5 4NR (Tel: 081 770 1151)*. If Motability request such an assessment, they will cover the cost of £50.

Troubled Children

A matter of growing concern today is the higher incidence of troubled and troublesome children in schools, particularly in the Secondary sector. Aggressive behaviour, child abuse and bullying are becoming more prevalent and more and more pupils are being excluded or being taken out of school. Children with spina bifida and/or hydrocephalus are among those who are suffering because of bullying, disruptive behaviour, fighting and teasing and, because of their disability, are unable to cope with the stress and anxiety caused. Often, children with disabilities have a poor sense of self-esteem and confidence in their abilities, which creates frustration resulting sometimes in aggressive behaviour to others. One way to overcome these problems is to create an atmosphere of understanding.

For many years now I have advocated greater parental involvement in schools (1) and teachers realise that a twice-yearly contact with parents at official parent evenings is not sufficient for a school mutually to understand the problems and needs of their pupils. It is important for a school to develop effective home/school links and create an atmosphere where relationships with parents can be improved. In a pamphlet issued by the Coventry Education Community project some years ago, parents were counselled: *Don't believe all they tell you about us or the children, then we promise not to believe everything they tell us about you. It's not that they tell us lies, it's just that they enjoy using their imagination. A very natural thing to do.*

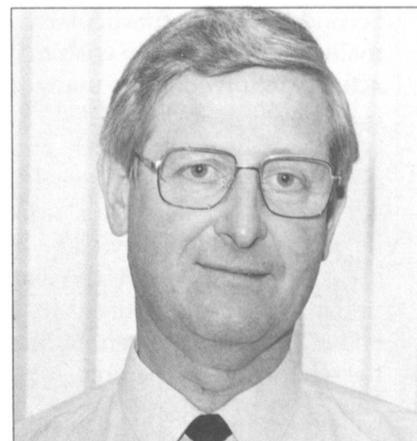
The fact that such a warning was necessary emphasises the need for a realistic and informed understanding of what happens in school. Most parents are interested in the effective education of their child and, if this is to be achieved, there must be collaboration

between all involved.

The principles which govern Teacher/Parent relationships are the same as those which govern all effective human relationships, mutual respect, liking and goodwill. In many instances they develop when we work alongside one another in order to complete some important task. We learn each other's strengths and weaknesses, the best and worst of each other's characters. In this way we learn to recognise the real qualities in an individual and to know a person as a unique and valuable member of society. If we are fortunate, we also learn more about our own capabilities and attitudes. (2)

A Mori Poll carried out for the BBC programme *Panorama* claims that the total number of pupils excluded from school may be as high as 65,000. Special Needs professionals are concerned that the mushrooming of exclusions is being fuelled by cuts in Special Needs support services.

Recently, I have had an increasing number of referrals about behavioural problems relating to pupils with hydrocephalus. In many cases these have been



Author Peter Walker, former headmaster and now ASBAH's Disabled Living Adviser (Education).

exacerbated by a lack of understanding of the difficulties of pupils with the condition by teachers, educational psychologists, parents and others. We must be aware of the many limitations being experienced. Pupils with hydrocephalus often get confused when bad relationships develop in schools. Their inability to remember in the short-term inhibits investigations into bullying and aggression. They cannot readily bring to mind how the 'incident' happened or who caused the problem. In some cases, because of frustration, they may or may not have caused the fracas but are unable to make any sense of the situations surrounding it. This means that the more articulate are able to gain the argument, resulting often in injustice and a reinforcement of a pupil's inadequacy and poor self-image. Schools and local Education Authorities must deal sensitively with such problems and, together with parents, enter into meaningful dialogue to resolve the situation.

The onset of puberty and an

increasing awareness of sexuality can also produce problems for pupils with learning and physical disabilities. Parents of such pupils are often confused about possible and appropriate sexual behaviour and are rarely given any opportunity to look at either the real problems or at possible solutions. Many disabled pupils at Secondary School (particularly mainstream) naturally wish to be actively involved in the many activities of their peer group, which involves forming relationships with the opposite sex. For many reasons this desire never becomes a reality and occasionally inappropriate sexual public behaviour manifests itself and is an embarrassment both to the school and the parents.

Gillian Penny (1989) in a chapter on "Pupils under stress" (3) suggests the following strategies for group discussions to acquire

skills for helping pupils to cope with some of the stresses that they have to cope with.

1. *Problem solving*: an important skill for pupils who have to develop life change, which includes how to identify problem situations and to achieve possible solutions.
2. *Developing personal resources*: helping pupils to think more positively about themselves and enhancing their feelings of competency makes them feel less threatened by life changes and enables them to take more positive action when faced with threatening situations.
3. *Developing support systems*: teaching pupils interpersonal skills - how to communicate effectively and be sensitive to others' needs and how to express feelings constructively. This has the added advantage of making them more

able to help and support each other.

4. *Gaining knowledge about helping agencies*: information about local agencies and sources of help should be made available to pupils. ASBAH is such an agency for providing information and advice about the learning and behavioural difficulties that may be encountered by students with spina bifida and/or hydrocephalus. It may be obtained by contacting the advisory staff at ASBAH House.

References

- (1) Walker P. *Parents' Rooms in Primary Schools: Philosophy and Management. Education Today* Vol 36, no.1, 1986.
- (2) Goodacre E.R. *School & Home* p.46. Slough NFER, 1970.
- (3) Penny G. *Pupils under Stress* in Reid, K (Ed) *Helping troubled pupils in Secondary Schools* Blackwell 1989.

Review



What About Us?

Sex Education for Children with Disabilities

ANN CRAFT & DAVID STEWART

The Home & School Council ISBN: 0 901181 70 6 Price: £2

Disabled children are too often viewed as without sexual feelings or sex lives. Consequently, they have sometimes had little or no sex education, from either their parents or school. If you are partially sighted or have learning difficulties, for example, many of the informal clues to appropriate sexual behaviour are not available to you, so you miss out. Physical disability can mean loss of the opportunity to learn, not loss of interest.

Dr Craft and David Stewart have written a very good booklet for parents about sex education for children with disabilities. Very easy to read, it helps the reader

follow through the thinking process for the need to give disabled children sex education. It acknowledges the problems the disabled child, parent and school have and does give a few ideas on how to move forward.

This booklet puts the views of the disabled youngster simply and positively in a concise form. It should be read by all parents who are unsure how best to communicate to their child an appropriate sex education. The authors look particularly at the relationship between the parent and school and suggest how, by working

together, they can give the best information to the individual child.

Obtainable direct from: The Secretary, The Home & School Council, 40 Sunningdale Mount, Ecclesall, SHEFFIELD S11 9HA; TEL/FAX: 0742 364181





P | E | R | S | O | N | A | L

Relationships



"Each day an adult produces, on average, two and a half pints of urine".

Two and a half pints. No problem for most people. An everyday problem for those with poor, or no, bladder control.

For many people with spina bifida, incontinence is a fact of life. There are other facts of life as well - sexual ones.

Teenagers and adults with spina bifida also enter into personal relationships. Incontinence may be an inconvenience, but not a barrier to enjoyment.

A new training package of video, audio cassettes, manual and illustrative materials has been produced to enable teenagers and adults with spina bifida and incontinence to discuss and explore issues that are of importance in personal relationships.

The need for the package - called *You, Your Partner and Continence* - was identified initially through an ASBAH-funded research project conducted by our research fellow Maddie Blackburn, who is based at Chelsea and Westminster Children's Hospital.

The people you see and listen to in the video are all adults with spina bifida and/or hydrocephalus. It is their views, their opinions, which are represented. They speak frankly, courageously, and with emotion. A consumers' panel was consulted throughout.

The panel's view at completion:
"Get it into distribution as fast as possible."

The package was produced by Imogen Carlton, a third-year Design and Media Management student at Thames Valley University. The university hosted a press launch on 2 June.

The video is designed to promote discussion. It can also be used independently. To facilitate questioning and learning, the facilitator or viewer can view it section by section and initiate discussion with those viewing.

The people in the video talk about the difficulties of lack of continence - from the social embarrassment of smell to techniques that could be applied to control continence when engaging in sexual intercourse. In order to provide simple but effective images, simple line drawings, photographs and computer-video graphics are used to demonstrate techniques ranging from urine control to catheterisation.

The audio tape is essentially the sound-track of the video and provides an audio version for those who, either for reasons of memory or poor vision, would prefer an alternative to the video.

The handbook provides additional information to that given on the video. It has been written with the consumer rather than the professional in mind.

Potential users: continence advisers, nurses, personal relationship counsellors, teenagers and adults with spina bifida, spinal injury units.

The use should be restricted to people who are aged 16 and over.



Maddie Blackburn (above), ASBAH's research fellow, works with Dr Martin Bax in the Academic Department of Child Health in the new Chelsea and Westminster Hospital.

Imogen Carlton (below) is a third-year Design and Media Management student at Thames Valley University. The training package has been produced as part of her course work.



You, Your Partner and Continence contents: one VHS video (running time 18 minutes); one A5 handbook, 20 pages; one audio cassette (12 minutes); illustrative materials, including a catheter and a contraceptive.

Prices:

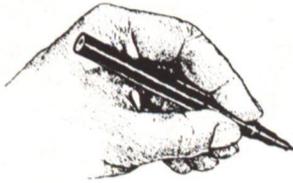
£25 (inc VAT and p&p) to disabled adults

£45 (inc VAT and p&p) to organisations

£55 (inc VAT and p&p) overseas orders

Hiring: ask ASBAH information office.

To order: Information Department, ASBAH House, 42 Park Road, Peterborough, PE1 2UQ.



Letters



I am the mother of six-year-old Brian who has spina bifida and

hydrocephalus. He had surgery when he was three days old to close his back and within the next two weeks he developed hydrocephalus: he got his shunt in and since then has only had it lengthened.

We travel 150 miles to and from the Royal Victoria Hospital several times a year to have him checked. We used to go into his consultant then go over to see his orthopaedic surgeon. But, nearly three years ago, everyone was told that we couldn't go over because that clinic was for fractures only. I had to go over and ask the spina bifida consultant to get Brian seen by Mr Graham, the orthopaedic surgeon as he couldn't sit or walk for months. After more than three hours waiting he hadn't much time to look at Brian and said that if he didn't get any better to get in touch.

Two years ago I had Brian referred to our local hospital. They were willing to accept him but Mr Wray said that he did not specialise in spina bifida and, if anything did go wrong, he would have to refer him to Mr Graham so he said he would recommend that Brian stayed a patient of Mr Graham's.

Mr Graham then sent me an appointment for Brian, he told me that he could do nothing to solve the problems that we had. He told me the fractures were more important in the short term and that he had no time to give the spina bifida children the care they needed. He said there was another fracture hospital closing down and he had to see all those patients as well, and the only spina bifida

patients he could see were newborn children.

Brian was ordered a pair of splints in December two years ago - he didn't receive them for eight months. He was ordered another pair four months ago and we still have not received them. His feet are all blisters and lumps of hard skin because of his splints.

We have been to everyone we know who we thought might help but we have got nowhere. Mr Graham is a great surgeon but he hasn't got the time he needs for our children. We all would love to know why the only orthopaedic specialist in spina bifida in Northern Ireland has almost all of his time taken up with fractures.

Pauline Clarke, Derry, Northern Ireland.



I have never made a decision not to educate myself about

hydrocephalus. I just felt when Mary was born, especially being separated from her for five days that bonding with her was more important than burying my nose in a text book. When the pressure sore (at the shunt site) burst Mary was very poorly and I was too worried about her to think about much else.

Being a nurse I feel that I have enough knowledge already to look after Mary at home, confident that I would notice signs of raised intracranial pressure.

The questions that I didn't feel ready to ask were about brain damage. I needed to come to terms with being a mother first.

Obviously, not being a neurosurgeon myself, I have to leave the doctors to operate on

Mary. If I felt something was wrong with the shunt, however, I would certainly speak out. I do feel lucky that Mary is under the care of Great Ormond Street though.

One last point - I could never have got through the first eight weeks of Mary's life without the endless help and support of my family and friends.

Carrie Nesbitt-Larking, Welwyn Garden City.

■ "A parent, in sickness and in health" page 14



I am an ex-student of the National Star Centre in Cheltenham, and last

weekend I went to the Reunion there which is held each year. I was absolutely mortified to hear that the college has had to make eight members of the staff redundant to save costs as they need £100,000 to keep the college up and running as soon as possible or else the college may be shut in the next couple of years.

Please could you let your readers know about my plight as I am in the process of setting up a fund for sponsorship for this project. We need as many people as possible to help us raise this money through sponsorship.

I have sent away for sponsor packs and forms so if anyone would like to do an event to help us raise this money, please could they contact me urgently at the address below so I can send them the form and pack. Thank you.

Lisa Clark, 33 Elmscote Road, Easington, Banbury, Oxon OX16 9EQ

We'd like to hear from you.

Send your letter to:

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Bromakin Racing Wheelchair, excellent condition - as new £400 ono. Tel: Sedgley (0902) 679430.

EPC - Equipment for the Physically Challenged (a company run by the disabled for the disabled). New and second hand lightweight wheelchairs. Authorised dealers for Action Technology, Quickie and Swede. Home demonstrations, wheelchair insurance, advice. For further information, please ring 0252-547939, or our new office in Coventry, 0203-422327.

LINK Rates

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Cheques and postal orders should be made payable to 'ASBAH'.

Small adverts for the next issue of Link (August) should be submitted by Friday, 2 July. Please send them to the Editor.

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