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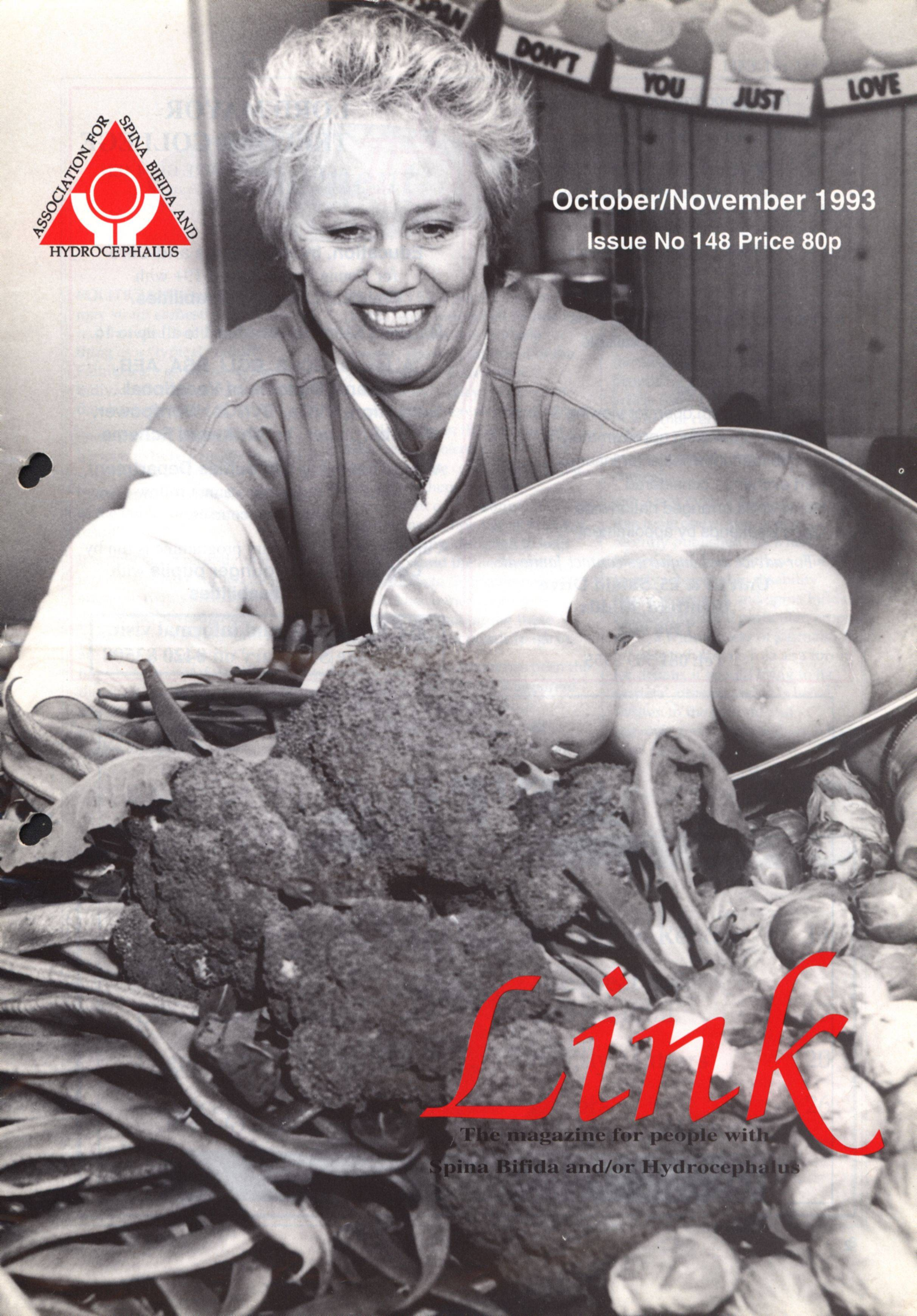

October/November 1993
Issue No 148 Price 80p

Link

The magazine for people with Spina Bifida and/or Hydrocephalus

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Comment

POLITICIANS and statisticians may strain earnestly to persuade us otherwise, but there is no such thing as a "typical" family. Families are as varied as the individuals they comprise - and thank goodness for it!

Should one of those individuals happen to have a disability such as spina bifida and/or hydrocephalus, does the dynamic of the family unit change as a result?

It is only fairly recently that researchers have turned their attention to this area, and it is clear that further investigations, particularly of a long-term nature, are needed. "Snapshot" studies have been successful in identifying the questions we should be asking and in this issue *LINK* offers its own contribution to the discussion (pages 20 - 25).

WHATEVER a particular family's profile, each individual member needs to be housed - *suitably* housed. The general thrust of the government's 'Care in the Community' policy places great emphasis on encouraging disabled people to live in the community. Less openly voiced is a desire to keep down the costs of residential care. Why, then, does the Department of Environment's recent consultation paper threaten the very grants designed to help people to fund the necessary adaptations to their own homes? ASBAH has joined a group of charities in condemning these short-sighted proposals (page 6).

DIFFICULT to fathom has been the Department of Health's apparent reluctance to embark on an education programme to raise public awareness of the need for including folic acid in the diet of any woman planning a family. The medical facts have been known for two years, and guessed at for much longer; some individual companies and agencies have been working hard to get the message across. At last - literally as we go to press - we have received a draft from the DoH of a proposed information leaflet. ASBAH's comments have been invited. We will bring you more details with the next issue of LINK -it's a promising sign! Kate Douglas's article *(page 17)* raises the question of whether certain foods should be fortified - but would such a measure remove individual choice?

NO APOLOGIES for including in this issue one or two articles recently published elsewhere. Material relevant to those of us keenly interested in disability issues in general, and spina bifida/hydrocephalus in particular, crops up in a wide variety of journals. If *LINK* is to fulful its role as a forum for debate, it should bring to its readers' attention what is being written in the general and scientific press: information, it has been said, is power!

Jeanette Dixon

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Cover: An abundance of food rich in folic acid is to be found in the market place! (see "The great folic acid scandal" page 17)

National Key Scheme

The National Key Scheme (NKS) was introduced because an increasing number of local authorities and other organisations providing public toilets believed that they had to lock their toilets either totally, or for many hours, to counter vandalism and in order to reduce costs. Unisex toilets designed for use by disabled people are particularly likely to be made unusable.

If toilets for disabled people do have to be locked, local authorities and others are asked to join the NKS which involves fitting standard locks to their toilets and making keys available to disabled people. This has now been adopted by over 300 authorities throughout the country. Nearly 3,000 toilets have been fitted with the NKS locks including those at a number of seaside resorts and other areas attractive to visitors. British Rail and a number of other organisations have also joined the scheme.

The scheme is not in use everywhere - unfortunately, a number of local authorities do not have any suitable toilets and, more happily, others do not have vandalism problems. However, it is hoped that as many authorities as possible will participate in the distribution of keys to disabled people and that they will be widely available from Information Centres, etc.

For those who are unable to obtain an NKS key in their own locality, RADAR supplies **keys** at a charge of **£2.50** for disabled people and **£2.94** for non-disabled people who must pay VAT, hence this higher price. A list of toilets fitted with the NKS lock is available as a **book** priced **£3.00**.

Although it is not RADAR's policy to encourage the locking of public toilets for disabled people unless absolutely necessary because of vandalism and misuse, they feel that this scheme at least offers some measure of independence to key holders, who do not have to rely on attendants to open the toilets.

RADAR, 25 Mortimer Street, LONDON W1N 8AB.

Stationlink

NEW arrangements for users of Stationlink buses have come into force at Paddington Station, London, with the setting-down and picking-up point moved to the main concourse, opposite platform 9, instead of in the taxi arrivals road. Stationlink is London Transport's fully-accessible inter-station bus service, linking London's mainline stations in a clockwise circular route.

Car Stickers

Have you ever felt frustrated when someone parks in a disabled parking bay illegally? Did you know that you can buy a pad of 100 tickets to remind people politely that they are parked in a space reserved for orange badge holders? It will only cost you £1.70 and may save your blood pressure!

A Bristol firm produces a whole range of notices and stickers for disabled drivers, including SOS signs for requesting help, and signs to warn people not to park too close. If you are interested they will send you a leaflet with prices and an order form.

GPSP Ltd., PO Box 25, Portishead,
BRISTOL BS20 9NJ

Individual Membership

ASBAH is to give its army of private supporters an opportunity to have their support of the Association recognised in a constitutional and practical way.

With immediate effect, the Executive Committee has launched a new category of individual membership which will give individual members the vote at meetings of Council.

The fee for individual membership has been set at £17.50 a year for 1993/4, and this should be included with the application form which is obtainable from Mr Derek Knightbridge at ASBAH House.

But the fee will be waived for people receiving Invalidity Benefit, Disability Working Allowance, Family Credit, Income Support or Severe Disablement Allowance. In these cases, the forms will ask applicants to state what benefit(s) they receive. This information will be treated in confidence.

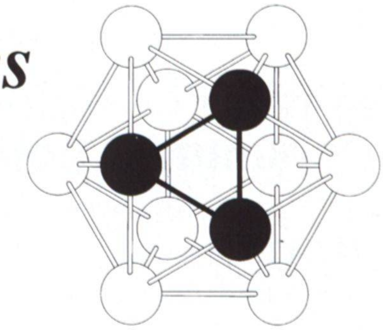
Initially, there will be a top limit on numbers of 200 individual members.

The Executive Committee hopes that this category of membership will attract people who wish their support of ASBAH to be formally recognised.

Besides voting rights at meetings of Council, the membership package will include the following items which will be sent to individual members: a copy of the *Annual Report and Review*, a year's subscription to *LINK*, a copy of new and revised information sheets as they are published, an ASBAH diary and the latest *Guide to Services*.

Applications must be approved by the Executive Committee, so there may be a time lag between the application being received at ASBAH House and notification of election. But a letter will be sent to each applicant pointing out the date of the next Executive Committee meeting when it is hoped election will take place.

Blood samples might hold the key



BRITISH scientists hope within two years to be able to identify the genes which cause spina bifida.

To help them on their way, a team in Newcastle wants to receive blood samples from ASBAH families. These could help unravel one of the great mysteries of life - what predisposes some people rather than others to spina bifida and other neural tube defects.

The team is focussing on two different sets of genes in human DNA.

While nobody claims that victory is in sight, success might pave the way for a magic bullet treatment which could eventually remove the defect from the genes.

The work has just started in the division of human genetics at the University of Newcastle upon Tyne, where one set of newly identified master genes has recently been identified. These control other genes, thought to be important in the development of neural tissues and vertebrae.

Interest is also homing in on another set of genes, but the identity of these is being kept secret in order to preserve confidentiality.

Clinical co-ordinator Dr Sally Ann Lynch wants to hear from any family, where there has been reoccurence of spina bifida or anencphaly, who wants to donate blood samples to the Newcastle study. She will then arrange for the blood to be taken from affected individuals and their parents.

For readers outside Newcastle, the collection can be done by qualified staff at home, at a GP's surgery or in a treatment centre regularly used by the patient. Blood samples are already being sent to Newcastle from Northern Ireland and Dublin, where collaborative arrangements with other centres have already been set up.

"If we are able to identify some of these genes, then we will be able to understand how and why neural tube defects arise. We will also be able to identify 'at risk' people within a family group as well as in the general population", said Dr Lynch, senior registrar in medical genetics at the Royal Victoria Infirmary, Newcastle.

"Research projects can be long drawn out. We may not be able to give you any results from the test for many years, if at all. However, if we discover any genes that are important as a cause of neural tube defects in your family, we will be in contact - if people taking part want us to be", she added.

Offers of blood samples to: Dr S A Lynch, Senior Registrar in Medical Genetics, Dept of Genetics, 19/20 Claremont Place, Newcastle NE2 4LP. Tel 091-232 5131, ext 24798

Officers & Staff

"Good housing must be an essential component of Care in the Community policy" - says ASBAH.

THREATS of a cash squeeze on Government-funded grants aimed at encouraging disabled people to continue living in their own homes have been condemned by a group of charities, including ASBAH.

If the threats to the Disabled Facilities Grants become reality, the charities said many people will lose the only chance they have of finding the money to pay for home adaptations or extensions vital to basic needs.

"They will be forced to cope in unsuitable and possibly dangerous housing or will have to move to institutional care", say the nine charities in a joint response to proposals contained in the Department of Environment's recent consultation paper, 'The future of private housing renewal programmes'.

The consultation paper undermines the foundations of the Government's own 'Care in the Community' policy. It includes abolition of DFGs as an option.

It proposes, from next year:

- Slashing a third off the grant available to local authorities to help them improve the nation's private housing stock. This would reduce Whitehall support of slum clearance and home improvement grants (of which Disabled Facilities Grants are a small part) to £260m.
- Reducing the limits on mandatory grants available to individuals from £50,000 to £15-20,000.

Proposals mooted for introduction from April 1996 include:

- Allowing local authorities complete discretion in the awarding of DFGs, and in setting up their own means-testing procedures.
- Delaying the approval of applications from a maximum six months to two or three years.
- Cutting mandatory grants further to an upper limit of £5,000.
- Abolishing DFGs altogether.

"It offers no justification for this substantial reduction in resources at a time of obvious, great housing need", commented Mike Ellison, policy officer for Care and Repair, the charity which co-ordinates voluntary work aimed at helping elderly, disabled and low-income people to keep in their own homes.

In a separate response to the consultation paper, ASBAH executive director Andrew Russell commented: "Disabled people are strongly encouraged by policy to live in the community. Their families are encouraged to continue to provide care for them.

"Indeed, it is increasingly difficult for families or disabled people to secure funding for residential care."

He said the NHS and Community Care Act was introduced with the clear aim of reducing the growth in residential care costs. The government had a duty to facilitate an acceptable standard of housing in the community.

Much existing housing can be used, if suitably adapted, but it must be recognised that this was expensive and beyond the means of most disabled people or their families.

"It is not a sufficient response for government to distance itself from these problems, either by defining them as a local authority responsibility, or simply as a family responsibility", said Mr Russell.

Government departments had to move forward together to develop a common policy and approach, to solve the problems of disabled people. It was unlikely that this could be achieved without additional resources, because fewer disabled people would be admitted to residential care and more will be living in the community, and living to a greater age.

Government policy should, in ASBAH's view, assume that disabled people were autonomous adults, and not automatically the financial responsibility of their families. Therefore it was their individual resources and income, as disabled people, that should be assessed, except when a significant increase in the value of a property will be occasioned by extension/ adaptation.

"We welcome the suggestion of special circumstances where it would be possible to disregard the income of the owner, where he or she is not the disabled person. Where the owner is not in any case related to the disabled person, and where no significant increase in the value of the property will be occasioned, there is no case for taking the income or the assets of the owner into consideration."

Repeated representations on the Disabled Facilities Grant have been made to the Department of the Environment, to the effect that the financial outgoings as well as the income of claimants should be taken into consideration.

"We refer particularly to commitments on housing costs (mortgage or rent commitments), and extra living costs resulting from disability. Many claimants are prevented from taking up grants because of their assessment of their own contribution (or their family's). This is why the Disabled

Facilities Grant is so often ineffective and impracticable," he added.

"The success of the Community Care policy will depend on accurate assessments of needs by Social Services Departments, and proper provision to fulfil these needs. Because housing needs and care needs fall under the responsibility of separate government departments, at national and local level, it is essential for effective services delivery that responsibilities and procedures are clearly delineated and properly funded."

Commenting on the inclusion in the consultation paper of a section on abuse of the sytem, Mr Russell said ASBAH regretted it was placed so close to the section on disability.

"ASBAH has a countrywide network of professional advisory staff and local Associations, and we know of no abuses by disabled claimants. The section on abuse seems intended to cast doubt on the integrity of claimants on the inadequate basis of professed 'anecdotal evidence'."

Tony Britton

Wharfedale

Wharfedale is a small block of four flats, managed jointly by Sanctuary Housing Association and ASBAH, situated in Ben Rhydding, a quiet suburb of Ilkley in West Yorkshire. There are just two floors, with ramped access to the upper floor. All the flats are fully adapted to be wheelchair-accessible, and help and advice is given to new residents to ensure further adaptations are carried out if necessary.

Wharfedale benefits from having a Warden Alarm Call System; 24-hour cover is provided by staff at the Five Oaks Centre just a few yards away. A Housing Support Worker provides advice on housing issues, benefits, adaptations, access, mobility, local amenities, leisure facilities, employment opportunities and local health care services.

Applications are welcome from people who would be interested in living at Wharfedale with a view to establishing a waiting list. It is already expected that there will be two vacancies in the near future.

People with differing disabilities can apply but preference will be shown to those people with spina bifida and/or hydrocephalus.

Application forms can be obtained from Mark Best, Five Oaks Centre, Ben Rhydding Drive, Ilkley, West Yorkshire LS29 8BD, tel 0943-817673 or 0943-609468.

Help & Advice

Members seeking help and advice on any matters should make initial contact with ASBAH as follows:

London, Surrey, Kent, Sussex

123 East Barnet Road, New Barnet, Herts EN4 8RF. Tel: (081) 449 0475
Regional Co-ordinator: Gina Broughton.

Northern Ireland

73 New Row, Coleraine, Northern Ireland BT52 1EJ. Tel: (0265) 51522
Regional Co-ordinator: Meta Harvey.

Rest of England and Wales

National Centre, 42 Park Road, Peterborough PE1 2UQ. Tel: (0733) 555988

Mobility Roadshow 1993

The Motor Show for People with Disabilities

Prince Charles opens the show.

The first Mobility Roadshow was held in 1983 and has been held every two years since then at the Transport and Road Research laboratory, Crowthorne, Berkshire. It demonstrates a range of adapted cars for people to see and test-drive on the extensive off-the-road track. Special vehicles, powered wheelchairs, caravans and minibuses and many other mobility aids are on display, plus stands of various disability organisations, insurance companies, motor clubs etc - in fact, anything and anyone connected with mobility and the disabled person. This year the Roadshow was officially opened by HRH the Prince of Wales, accompanied by Minister of Transport John McGregor.

ASBAH had a stand as usual, manned by Liz Clayton (ASBAH's fieldworker for Berkshire) and disabled living adviser Leonie Holgate. They were visited by over 200 people representing local authorities, Social Services and resource centres, therapists, client group (old friends and new), driving instructors and many others. It was exciting and encouraging to meet so many young drivers using wheelchairs, some of whom had been on the ASBAH driving courses.

The emphasis of the show is undoubtedly not on whether someone is able bodied or disabled but on *people* and helping them to become mobile in the best way for them. There is every opportunity to try bicycles, mobile standing frames from Italy (Liz and Leonie were invited to 'taste' the electric-operated frame!), cars and so on.

Some scenes will remain with them for a long time: a young couple walking hand in hand and side by side, chatting animatedly, the girl in a wheelchair propelled by her partner's grip on her hand; a small boy in an electric chair with friend on stabilisers and smaller brother on his lap (not very safe, but it was obviously fun and they were making rapid progress!); another young couple with their baby in a seat attached to the front of his mother's chair and facing her, baby and mother able to keep an eye on one another.

It is definitely a show to recommend - so look out for June 1995!

Be your own boss

If young people would like to be their own boss, they should contact The Prince's Youth Business Trust. The Trust helps young people up to the age of 30 set up in business by offering advice and finance.

Grants are given of up to £1,500 and loans of up[to £5,000, with very reasonable terms of repayment.

"Applicants must have a viable business idea with the enthusiasm and determination to succeed. They must also have tried but failed to raise all the necessary finance - the Trust is a source of 'last resort' funding", commented assistant development manager Alison Tancock.

Further information: The Prince's Youth Business Trust, 5 Cleveland Place, London SW1Y 6JJ, tel and minicom 071-321 6500.

Magic Flute!

Beverley Whyte has just embarked on an MA in 20th Century music, after graduating with first class honours from Queen's University Belfast this summer. She started playing the flute when she was 15 years old after, as she puts it, "two rather unsuccessful years of learning the violin!

"I play a few other instruments - piano, guitar and tin whistle. This last I took up as a traditional Irish instrument to play in an international Very Special Arts Festival in Washington DC in 1989, at which I performed to an audience at the Kennedy Centre."

Although Beverley enjoys playing Romantic and 20th century music, her degree was based mainly on composition and she is keen to develop her own skills as a composer. The composition course she attended in Avignon in July was "an absolutely fabulous musical experience where I began to discover my real compositional style.

"As for my flute playing, I hope to continue playing with the QUB orchestra and in the 18-piece contemporary jazz ensemble called 'Maverick Wurlitzer'."

Beverley Whyte

Kevin makes legal history

AN INVENTOR has brought a revolutionary new baby walker to market after an epic 'David and Goliath' battle took him to the highest court in the land.

Kevin Daily launched his 'Jo-D Walker' at the *Naidex93* exhibition in London last month - after fighting a seven-year court battle which ended in the House of Lords and ran up £35,000 in legal costs.

Mr Daily, whose 10-year-old daughter Joanne has spina bifida, invented his baby walker in the mid-eighties after being unable to find one safe enough for her in the shops.

Consumer research at the time revealed that some models were unsafe because they could tip over easily or catch alight near unguarded fires.

Mr Daily designed an untippable walker with a centre of gravity so low it virtually goes through the floor. There are no handles or bars for small hands to get caught in. The frame is clad in rigid, almost indestructible, plastic.

And he patented two mechanical features - an automatic brake that holds the walker stationary as the child pulls itself to its feet, while gripping a unique arrangement of sloping non-slip bars. When the child is standing upright, its weight is then evenly distributed across the frame permitting the release of the brake and allowing the child to move off.

Seven years ago, production was ready to start. Investors were waiting in the wings. Then a major French company started selling another baby walker looking like a train but with remarkably similar mechanical features, called the Locopousse, in British stores. The investors got cold feet and pulled out.

Kevin Daily, clinging to a brilliant set of ideas he was determined to protect, starting taking on the big boys. In the process, he made legal history.

He took action in the High Court to protect his patents but costs mounted so quickly he was forced to withdraw. Then the Patent County Court, offering inventors cheaper access to justice, was set up.

Mr Daily, seeing his chance, became the first plaintiff to appear before it. He won his action for patent infringement.

But the UK distributor Argos, importing from France, became the first appellant of a Patent County Court decision. They argued that they had not infringed Kevin Daily's patent, with the discussion hinging on the technicality of whether or not the braking system on their Locopousse was "associated" with the rear wheels - the Daily patent.

After several twists and turns, the Court of Appeal upheld the appeal last year. The Appeal Court decided that the Locopousse became stationary because, when a child pulled itself up, the Locopousse touched the floor. There was no "association" with rear wheels.

The Appeal Court decision was unsuccessfully challenged by Mr Daily on a point of law in the House of Lords earlier this year.

The Jo-D Walker is being manufactured by Kevin Daily's company, Hazeldean Developments, and sold at £129, subject to VAT where it is payable. Allow 28 days for delivery.

The company say it is a bright lightweight walker with maximum all-round stability. Eight pneumatic foam tyres give a smooth ride and the walker will give a child more confidence in its own abilities.

ASBAH readers can claim a discount which reduces the price to £119, plus VAT where payable. For more details, tel or fax 0353 698023.

"We put up one hell of a fight but lost the argument over this one word "associated', said Mr Daily at his home in Little Downham, near Ely, Cambridgeshire.

"At one stage things got so rough and we seemed so close to winning because we had private detectives watching the house and talking to neighbours to find out if we were claiming legal aid rightfully. I am more determined than ever to make a success from my invention."

A computer first?

ASBAH has set up a computer servicing company - in a revolutionary bid to make new money to help fund our charitable activity and pave the way for service expansion in the years ahead.

The company, Computer Sense Ltd, started trading at the beginning of September. It will become fully operational when it moves into its new workshop at Hemel Hempstead at the end of October.

Joint managing directors John D'Arcy and Gwyn Martyn, who have both built up their reputations in the business by working for others, will be covering the Home Counties and North London in the first instance.

"They are both highly professional operators, full of ideas and with the determination to carry them through. We have no doubt that their business will be contributing in a major way to ASBAH's success within two years", said ASBAH finance director Derek Knightbridge, who is on the board of the new company.

"Computer Sense is a wholly-owned subsidiary of ASBAH. What makes it unique, we think, is that it is the first computer firm in the country which gives all its profits to charity. This will be a major selling point."

The company, in the process of taking on another skilled engineer, can handle every desktop computer need - from repairs and maintenance to the supply of paper and ribbons. Apple will be a speciality.

John D'Arcy, who worked for a small company which turned over £5m two years ago, said he hoped to land substantial contracts shortly.

The company chairman is Brian Henley, who is a member of ASBAH's executive committee. He commented: "The next nine months will be the testing period, but CSL has tremendous potential both in terms of the skills and energy available and demand for its services. Give them a call to see what we mean."

UN's new day for disabled people

THE United Nations has designated 3 December 1993 for the first-ever *International Day of Disabled Persons* - with the intention of writing the date into the calendar every following year.

The UN's stated aim is: "The achievement of the full and equal enjoyment and human rights and participation in society by persons with disabilities."

Disabled People's International - European Community Committee (DPI-EC) is helping to bring the International Day to Europe. Throughout the European Community, 3 December will in future be the *European Day of Disabled Persons.*

According to DPI-EC chair Rachel Hurst, the aim of the Day is "to show Europe that disability is an equal opportunities and human rights issue. The Day will be used to alert EC institutions, national governments and a population of 360 million people to the contribution that 41 million disabled people could make to the Community, if discrimination ceases and equal opportunities are implemented."

Many activities are planned to take place across Europe but the highlight of the first European Day will be a European Disabled People's Parliament. This unique forum will be made up of 518 disabled people chosen by national organisations which are members of the European Disability Forum (HELIOS).

The event will take place in Brussels and it is planned to stage it in the European Parliament.

Details: DPI-EC Office, 11 Belgrave Road, London SW1V 1RB, tel 071-834 0477.

Anencephaly

Anencephaly is a fatal maldevelopment of part of the brain and skull which occurs during the first eight weeks of pregnancy. The upper part of the brain and the overlying skull cap are absent although the lower part of the brain and the base of the skull do develop to some extent. Female babies are more commonly affected than males.

This abnormality occurs in about one in 1000 pregnancies. Its incidence is highest in those areas where spina bifida and hydrocephalus are common, and, in fact, anencephaly and spina bifida can be present together in the same infant. The risk of anencephaly and spina bifida occurring in further pregnancies is one in 50 if it has happened once, but it increases to one in five if it has happened twice. It is therefore essential that the mother takes a folic acid supplement before conception and for the first twelve weeks of any subsequent pregnancy.

Anencephaly can be detected by ultrasound scans as early as the 14th week of pregnancy if the baby is lying in a favourable position. Most cases are detected by the 20th week of pregnancy. If further confirmation of the diagnosis is needed amniocentesis is carried out and the level of the alpha fetoprotein in the amniotic fluid can be measured; the level is abnormally high in this condition.

If the pregnancy does go to full term the babies are either still born or die shortly after birth. Understandably most parents opt for a termination of pregnancy once the diagnosis has been made. During subsequent pregnancies scanning is carried out to make sure that the abnormality has not recurred.

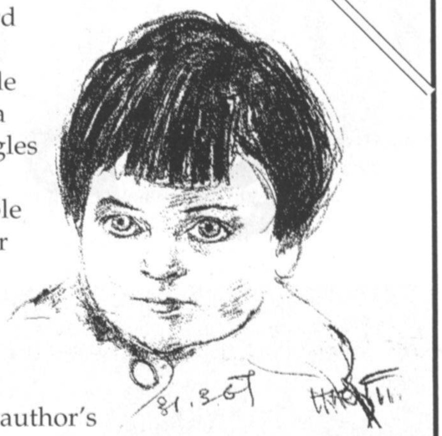
Carys M. Bannister
Department of Neurosurgery
Booth Hall Children's Hospital, Manchester

Angel in White Boots

REVIEW

EDDIE POWELL

This is a moving, well written record of the life of the author's daughter, Angela, who was born with multiple physical handicaps, including spina bifida. The book narrates her struggles to achieve a degree of normality, in which she succeeded to a remarkable extent. The heartache of seeing their daughter's almost superhuman attempts to do the things that most other children would find easy makes a poignant account.



There are also implications for the author's marriage. The trials and tribulations of bringing up a disabled child have undoubtedly strengthened the relationship between Eddie and his wife Mary, who celebrate their 39th anniversary this year.

In spite of the sudden, tragic ending to the story, it is an encouraging narrative of the triumph of love over adversity. It will act as an encouragement to those who are caring for a disabled child. Truly, it seems, love *can* conquer all difficulties. When you read the book you will appreciate the meaning of the title. It is written in fourteen chapters in a style that makes for easy reading, and I for one found it difficult to put down.

Carol Ashworth

"Angel in White Boots" is obtainable from Mary and Eddie Powell, Corner Cottage, Water Lane, West Runton, Cromer, Norfolk NR27 9QP. Price £5.70 including p&p.

Spinal Research

Reports in the press concerning research into the regeneration of central nervous system cells have prompted some enquiries to ASBAH as to whether recent advances - which may eventually benefit people who have incurred a spinal injury - may also benefit people with spina bifida.

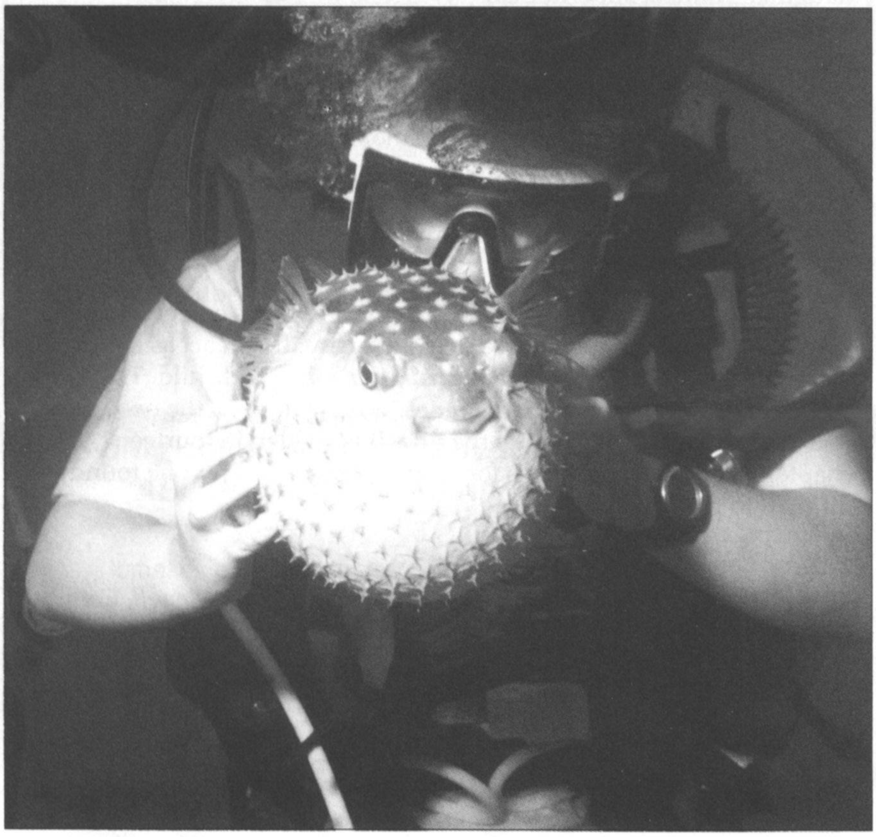
According to Peter Banyard, Research Director at the International Spinal Research Trust which sponsors these studies, it "would be wrong to suggest that the help would be more than marginal.

"In a traumatically damaged spinal cord, the problem is one of severed fibres and not so much one of nerve cell death. The prime aim of our strategy is to provoke the regeneration of the damaged fibres and their reconnection with the existing alpha motor neuron cells. This is a very difficult task but still much simpler than the generation *de novo* of a spinal cord which has failed to generate properly in the first place."

Obviously, this research is at a very early stage but it seems unlikely to prove of direct relevance to spina bifida.

The underwater world is a wonderful kaleidoscope of colour and noise with exciting surprises awaiting you on every dive where, writes STEPHEN WALSH, you can discover

INNER SPACE



SCUBA diving has become a safe, fun and relaxing recreational activity. It is not so much a *sport* - it is not competitive - as a chance to meet people, socialise and discuss the excitement of your diving experiences. You dive in 'buddy' pairs and assist each other.

OUR DAUGHTER Caroline, who was born with spina bifida, loved to swim - water was where she excelled! During a holiday in Cyprus in 1990 when she was 14, she decided to learn SCUBA diving. Little did she know then the new world of fun and freedom she was about to discover.

After initial training sessions in the swimming pool came the excitement of further training in the open sea. She qualified as a Junior Open Water SCUBA Diver and on her return from holiday joined the local British Sub-Aqua Club to continue her training.

Now the wonders of the underwater world are discovered anew with each dive Caroline makes. SCUBA diving allows her to experience the weightlessness felt by the outer space astronaut. For the diver this is the point of neutral buoyancy when movement becomes effortless and you hover in your new three-dimensional world.

Caroline has restricted mobility from below the waist so she moves underwater by arm-swimming breast stroke. She has so perfected this technique that she can now outswim and outlast her air better than other divers. During her most recent week's diving, at Salcombe in Devon, she found a conger eel whose body was the circumference of a football; many fish three feet long; and shoals of various brightly coloured fish all on the ship wrecks close to the shore line in eight to 20 metres of water. She also experienced the excitement and freedom of handling an inflatable dive boat and communicating via the marine VHF radio.

Home and away

British sea waters during August are about 16 degrees Celsius. To dive in these conditions it is essential that the disabled diver wears a dry suit. This encloses your body in thermal protection with waterproof seals at the neck and wrists; the rest of you is encased. This has its difficulties as the suit is made of either neoprene or membrane, which are not very flexible, and putting it on requires the assistance of your 'buddy'. The suit will restrict your movements underwater and almost immobilise you on shore, but it's worth it as you will be kept warm and dry for a dive of up to an hour.

Overseas sea water temperatures are warmer in the summer. (Winter temperatures can be surprisingly cool - down to UK summer levels!) Here - in the warm summer sea - is where the disabled diver can excel. Only minimal thermal protection is needed, such as a t-shirt or thin neoprene jacket, and is worn mainly for protection against abrasions. The water is clearer, with visibility of 25 to 50 metres depending on the location.

Caroline has had two diving holidays at Aqaba, Jordan - paradise! The Jordanians are so helpful as they jostle each other for the privilege of who will next push the wheelchair, serve the meal, carry the luggage. If ever there was a holiday destination for pampering the disabled, Jordan is it! When it came to diving, all our worries were taken away. Caroline would be pushed in her wheelchair to the water's edge, her equipment was assembled for her, she would enter the water where the equipment would be fitted to her. Then the instructors would take her diving, leaving everyone else to follow. As the dive progressed she was shown all the special sights, with the instructors propelling her by holding her hand. After her dive they would dekit her and wash all her equipment - what luxury! The sights that meet the SCUBA diver in Jordan appear as if a child has taken a paint palate and randomly splashed the colours throughout the aquatic environment. The colours and types of fish, together with the corals and marine growths, are mind blowing: SCUBA divers here initially use more air through sheer excitement! The Mediterranean is cooler and has less marine life but is just as much fun. Here again, in the summer the only thermal protection needed is a t-shirt. Diving in areas where the visitors do not go is rewarded with a variety of fish and marine growths. Cyprus has a number of shipwrecks. The largest, the *Zenobia* at Larnaca - a large roll on, roll off ferry - sank in 42 metres of water, the top structure being at 18 metres. Caroline took a hard boat ride to the wreck site from where she made two exploratory dives, the deepest being at 30 metres when she investigated the wheelhouse.

Wherever you dive, the fish life must be explored - indeed you can let them come and explore you! All fish creatures are very inquisitive and will come long distances to investigate your activity. We bang rocks together to 'call' them so they probably wish to complain about the noise we're making!

A 'sport for all'?

So who can SCUBA? Any person who is passed medically fit to dive. That does not mean you have to be super-fit - far from it. A disabled person would be examined by a medical diving referee who is an expert in knowing what conditions can be permitted. Being paraplegic or quadriplegic is not a medical restraint, nor is having a urine bag. Being blind is not a restraint, being deaf is not a restraint. Brain damage and seizure disorders *do* constitute a medical restraint.

Once you have qualified as a 'diver with disabilities' you will be restricted to diving with two qualified divers, or one nationally or internationally qualified instructor. You will find this can add to the enjoyment - practically, as your 'buddies' can assist with the heavy air cylinder, and socially, as you make extra friends.

Tempted? Then see the information panel for details of how to go about finding out more!

Caroline discussing diving experiences with her mum and diving instructor.

Opposite: Caroline Walsh holding a "puffer fish" in the Red Sea

How to find out more

There is only one organisation catering specifically for the needs of the disabled person in diving and that is *The Handicapped Scuba Association.*

Although the association is based in the USA, there are qualified instructors in the UK (the author, Stephen Walsh, is one) prepared safely to teach the diver with disabilities.

The British Sub-Aqua Club are gradually become more enlightened over catering for your needs, but it is a question of finding a branch who are prepared to accept the extra responsibility and time involved. One such is

Wet & Dry Sub Aqua Diving Club, Bognor Regis.
Tel 0243 826515.

Try also the liaison group

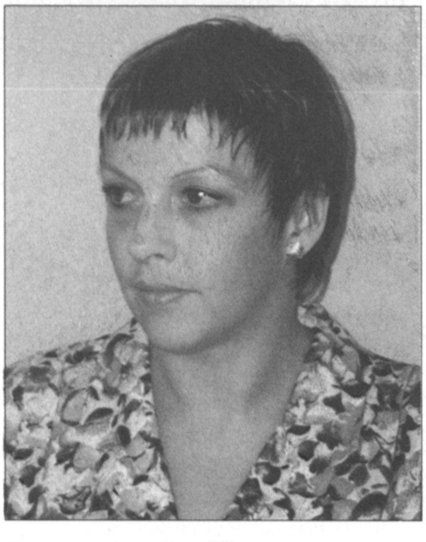
Dolphin, Plymouth.
Tel 0752 408093.

For more information and where to find your local instructor , you are invited to telephone the author on *081 859 6956.*

Incidentally - just in case you're wondering- SCUBA = self-contained underwater breathing apparatus!

Romanian Report

SUE HIRST, a fieldworker with ASBAH, was recently asked by a small local charity to spend a week in Bucharest as part of a team investigating the needs of the Association for People with Physical Disabilities. Was the aid they had already been sent getting through to the people who requested it? Was it appropriate to their needs? And what further help was required? Here she tells LINK readers about her experiences.



Sue Hirst

During our week-long visit to Romania we stayed with the doctor who had asked for our help, and our first trip after our arrival was to her surgery. The only equipment the doctors had were stethoscopes and sphygmomanometers, and these of very poor quality. They had no disposable syringes, only glass ones with no means to sterilise them; no large needles for injections - but,then, no drugs to inject either. They held a few out-of-date painkillers, but very little else. There was an air of futility about the surgery - what point was there in giving prescriptions for drugs that people could not afford?

Despite the fact that the doctors are highly trained - spending six years at medical school, three years as probationaries and a further three years to specialise in general practice or surgery - there is very little they are actually able to do in their ill-equipped practices. Even routine blood or urine tests have to be carried out at the Polyclinics as they do not have the necessary equipment themselves. This obviously incurs travelling expenses for patients who have little enough money in the first place. We had taken some drugs with us and were able to pass these on; more, I know, has been sent since.

We visited a hospital where the story was very much the same. It seems that everything is available, even surgery - but on the Black Market.

Our next trip was to the warehouse to see what aid had been distributed. We were all very shocked to see so much equipment, food supplements, clothing just piled up and not being used. We saw so much waste - food going bad, drugs now out-of-date. There is obviously a problem with distribution but I felt that perhaps the type of things being sent were not actually what people wanted, needed or knew what to do with.

We then began our visits to the members of the Association. All lived in very similar housing - Bucharest is a sea of large unsightly blocks of flats all built very close together. By law, any block over six storeys high had to have a lift. Regrettably, there was no law to insist that the lifts worked. Many people we saw had not been out of their flats for a long time. As wheelchairs are very difficult to come by, many had no means of transport anyway.

I think the phrase "before the Revolution" was probably the one we heard used the most. Although most people disliked the old regime, they all felt that for them things had been much better. Drugs were available, food was affordable, there was always water, electricity, gas. We visited a young boy quite severely affected by cerebral palsy - he shared his bed with three other brothers. In the past his mother had taken him regularly for physiotherapy but this was no longer available. She cried as she told us that she had no time to do it herself. She had eight children and both she and her husband worked every minute they could in order to earn enough to feed the family.

There is virtually no contraception. The public have been told that the Pill causes cancer; condoms are available on the Black Market, but at prices beyond most people's reach. Abortion is now legal up to 12 weeks of pregnancy, and any time after that if the mother's health is at risk or if she can afford to pay. Backstreet abortion is the most common form of "contraception". We were also told that there is no legal age of consent and that a large percentage of abortions are carried out on girls in their early teens - 13 or 14. No pre-natal tests are done at all.

I tried to find out the incidence of spina bifida but ran into difficulties. The doctor we stayed with had read about it but in 12 years had never seen a case. I managed to talk to the doctor responsible for the care of the Association members and she told me that it was rare - only two out of the 250 members had spina bifida. They were more used to hydrocephalus caused by trauma. We had trouble with shunt/valve translation and, despite a medical dictionary, eventually gave up! Our interpreter said (in her opinion) it's a condition we have because we (British) have no resistance - we boil water and take pills for everything, we are very weak people!

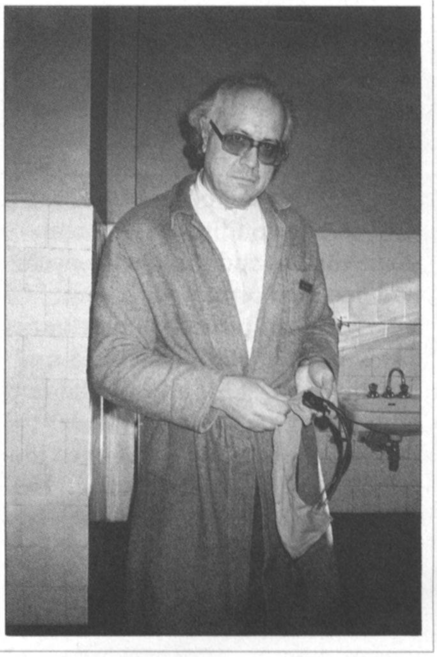
As we had expected, a lot of equipment had been inappropriately placed - self-propelling wheelchairs with people who were unable to propel and attendant wheelchairs for people able to self-propel. Penile sheaths had been distributed with little or no advice given on fitting. This led to a few light-hearted moments when I had to demonstrate on a variety of inanimate objects including candles and a perfume bottle (I lost the perfume,too!). We came across ill-fitting boots and calipers, even an artificial leg kindly donated but totally unsuitable. Food supplements like Fresubin had been given but with instructions in English, not Romanian.

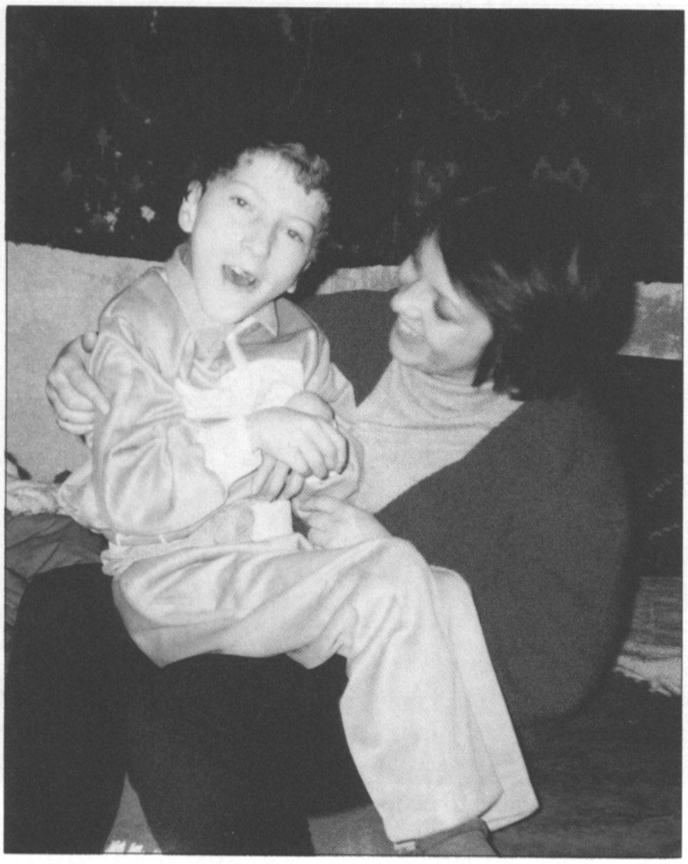
It is a country of anomalies. Each house, however poor, had a large television; most had videos - but not enough food. Although to us food seemed cheap, in proportion to most Romanians' earnings it is extortionate. Our hostess earned 20,000 Lei a month (about £30), but a piece of smoked meat which would last one person four days if they were careful, cost 3,000 Lei. I can't imagine spending 15% of a month's pay on one piece of meat.

We visited a girl who had been shot and paralysed in the Revolution. She had been rescued by the Red Cross and had

"Bucharest is a sea of large unsightly blocks of flats all built very close together. Many people we saw had not been out for a long time."
The splendid gold and marble of the House of the Republic Palace (above left) stands in sharp contrast.

The doctors in Romania are highly trained but must battle constantly in ill-equipped surgeries against disarray, confusion - even despair.





Twelve-year-old Christian has to share a sofa bed with two of his brothers. The physiotherapy he used to receive is now no longer available.

extensive rehabilitation. She had a lightweight wheelchair and more boxes of Lo-Fric catheters than I could count. She is unable to evacuate her bowels without microlax enemas but had only two left, and no prospect of getting more. For the past two months she had been using only one a week as her supply was low and was obviously feeling unwell as a result. We were able to leave 20 with her and you'd have thought we had given her the Crown Jewels!

We visited many people in devastating conditions. One man in his thirties had broken his neck, had been in hospital for a long time and then returned home to a flat with his mother. She lived up two flights of stairs and he had not been out of the flat since the day he got out of hospital, just over 18 months at the time of our visit. He had "invented" his own penile sheath and drainage bag out of plastic bags; he was delighted to find that someone else had made a slightly more refined version. There was little we could do to really help. It is very difficult to move flats, his mother was very poor and could not afford to bribe the officials. There seems to be a pension for people with disabilities but I could not find out the age it starts or what the medical criteria are. A few people we met received 4,000 Lei a month but as one young lady's drugs (anti-convulsants) cost her 3,500 Lei what she had left would only buy a bag and a half of sugar.

Many we saw had severe communication difficulties and were diagnosed as Oligophrenic, a term I have read in very old nursing books meaning severe mental handicap. None of these people had ever received schooling and it seemed that few ever went out. Many parents admitted leaving them alone during the day when they went to work as there was no-one else to care for them. There are no day centres or social workers; there are only the type of orphanages we have been made very aware of from our television screens. We were told by quite a few people that many more orphanages exist as well as many hospitals for babies and children with Aids, which is rife in Romania.

People with disabilities do not seem to be valued at all. We saw many people begging in the streets displaying their disabled relatives shamelessly - lifting shirts to show scars, pointing out amputated limbs. They are used as a way of making money by some.

For people with psychiatric illnesses, there is also little help. There are few beds available in psychiatric hospitals and these beds are for sale. Once admitted, there is only confinement, not treatment.

Although we really did not have much time to distribute help on this fact-finding visit, we were able to return to some of the people we had visited with equipment from the warehouse. We also visited a children's home and Michael Jackson's "Heal the World" playground which stands out with its brightly coloured swings and slides amongst an area of grey desolation.

We saw so many sad and moving things during our stay but one of the saddest to me was the constant feeling of despair in the people - the disarray, confusion, discontent and, worst of all, the shame. The doctors and nurses we met, the teachers, the interpreter all said they had no pride left in their country, which must be a terrible thing to feel.

And yet, if you visit the centre of Bucharest, you see a beautiful city. There are examples of wonderful architecture all around and the people we met were amazingly hospitable. It was my birthday while we were there and I - a stranger, after all, to these people - was given a wonderful party that I will always remember.

The Great Folic Acid Scandal

Kate Douglas

Government-funded research proved beyond doubt that one of the B-vitamins plays a powerful part in preventing common birth defects. So why isn't it in our daily bread?

AROUND half of all mothers-to-be in Britain and the US are surprised to learn they are pregnant. Usually they discover about two weeks after conception by which time their developing embryo is about the size of a full stop, and the neural structure that will eventually grow into the baby's brain and spinal cord has already formed. Disruptions of this process result in the most common birth defects in the Western world - defects that cause babies to be born with spina bifida or, worse still, without a brain. Yet with a safe and cheap dietary supplement in the first weeks of pregnancy, this is largely preventable. Unfortunately, by the time most women discover they are pregnant, it is too late.

The effects of folic acid - a B group vitamin - have been known for two years. Governments in both Britain and the US have accepted reports published by their health departments which state that folic acid can reduce these so-called neural tube defects by around 75 per cent. Both reports recommended that staple foods like bread should be fortified with folic acid so that all women of childbearing age get between 0.4 and 0.8 milligrams each day. But despite some vigorous campaigning by researchers, the food industry has yet to act.

Judith Hall, a professor of paediatrics at the University of British Columbia in Vancouver and a leading campaigner, has her suspicions about the industry's lack of urgency. "The whole area of congenital abnormality is perceived as a women's problem", she says.

Not just a women's problem

Fortunately for those campaigning for fortification, new research is proving her wrong. Not only does folic acid reduce the incidence of all forms of congenital abnormality, but it may also guard against heart disease in middle-aged men, according to recent findings in Ireland and the US.

Worldwide, as many as 400,000 babies are born with neural tube defects each year. In Britain, one in 500 pregnancies is affected, although annually only around 140 babies are born with neural tube defects because of screening and termination. For women who have already had an affected pregnancy the risk is up to 15 times greater, mostly, it is thought, because of a genetic predisposition. Racial variations also point to a genetic component. For example, conditions such as spina bifida are extremely rare in the US black population but common among Canadian Sikhs.

What causes fetuses to develop such defects remains a mystery. But records from the past 30 years show their prevalence to have varied considerably over time and from place to place - as well as according to race and social class. In Britain, neural tube defects are most common in Scotland, Ireland and Wales, and in the US the incidence declines markedly from east to west. A variety of environmental influences on embryonic development could explain these factors, but diet was implicated early on as a key factor.

In the 1980s, the hunt for dietary deficiency narrowed, and the breakthrough came in the summer of 1991 with publication of results from a Medical Research Council trial. Women who had previously had a pregnancy affected by a neural tube defect were given 4 milligrams of folic acid daily at least one month before conception and for the first three months of pregnancy. The result was a 72 per cent reduction in risk compared with those given a placebo.

Why folic acid should have such a dramatic effect remains unknown, although knowledge of how it works under normal conditions is what prompted the MRC investigation. In the human body it is converted to folate which helps enzymes to catalyse the synthesis of DNA and RNA. Deficiency results in slower cell division, most notable in rapidly dividing cells including red blood cells, which is why deficiency results in anaemia. Folic acid also seems to have a role in controlling the activities of genes. During normal development, millions of genes must be turned on and off. And one way genes can be deactivated is by DNA methylation, a biochemical process in which DNA is temporarily decorated with methyl groups.

Three ways to increase folic acid intake

1. Eat more foods rich in folic acid

These include green, leafy vegetables and certain types of meat. (Although liver is a good source of folic acid, pregnant women are advised not to eat it because of the high vitamin A content, which can be harmful to the developing baby). The following are particularly good sources:

- brussels sprouts - 110mcg
- asparagus - 155mcg
- spinach - 90mcg
- broccoli - 65mcg
- lamb's kidney - 75mcg
- Bovril (10g serving) - 105mcg

(Micrograms given per 100g serving unless stated.)

2. Eat more foods fortified with folic acid

These include certain, but not all types of breads (ordinary bread only contains 15mcg per slice) and breakfast cereals.

Bread (per slice):

- Mighty White Soft Grain bread - 40mcg
- Tesco Healthy Eating Bread - 40mcg

Breakfast cereals (per 50g serving):

- Kellogg's Special K - 250mcg
- Kellogg's Start - 190mcg
- Ryvita Cornflakes - 150mcg
- Tesco Fruit 'N' Fibre - 125mcg
- Kellogg's Bran Flakes - 125mcg

3. Take supplements

These supply about 400mcg of folic acid daily. Suitable supplements include:

- Solgar Folic Acid - 400mcg
- Cantassium Folic Acid - 400mcg
- Quest Multi B Complex - 400mcg folic acid, plus B vitamins
- Health Aid Pregnazon Multivitamins and Minerals - 400mcg folic acid, plus other nutrients.
- Berncard Pregnavite Forte F - 400mcg folic acid and other vitamins

Make sure you avoid tablets containing high levels or mega doses of any vitamins, and don't take several tablets with low doses of folic acid to reach 400mcg if this means taking high doses of other vitamins.

If you're in any doubt whatsoever about the dosage levels, always consult your GP. And if you're epileptic and on anticonvulsant drugs, you should consult your GP before taking a folic acid supplement.

Folate may be involved in supplying such methyl groups.

Everyone agrees that unravelling the precise role of folic acid in embryo development must await further research. Meanwhile, in the US, response to the MRC finding was swift. In August 1991, the Centers for Disease Control and Prevention at the Department of Health and Human Services issued an interim recommendation: women who had a previous pregnancy affected by a neural tube defect and wanted to conceive again should follow the regime used in the MRC study, and take 4 milligrams of folic acid each day.

Since 1991, other studies, notably one in Hungary funded by the World Health Organisation, have extended the MRC's findings by showing that all women can benefit from a low dose of folic acid. The Hungarians, using a daily dose of 0.8 milligrams and other groups using 0.4 milligrams - both rather arbitrary measures, but the most common doses found in multivitamin pills - have consistently found abnormalities reduced by around three-quarters.

Now the US Centers for Disease Control and Prevention recommend that 'all women of childbearing age in the US who are capable of becoming pregnant should consume 0.4 mg of folic acid per day'. The higher dose for women who have already had an affected pregnancy still stands. In Britain, the Department of Health made similar recommendations in its report, published last December. It also advises women intending to become pregnant to take a supplement and continue until three months into the pregnancy. All women are urged to eat plenty of foods rich in folic acid, such as green leafy vegetables, whole grains, wheat germ, salmon and root vegetables. These natural sources at present account for between 0.1 and 0.2 milligrams of the nutrient in the average diet.

Experts agree, however, that diet alone is unlikely to provide enough folic acid. So what steps can be taken to ensure that all women get at least 0.4 milligrams each day? Multivitamins are not necessarily the answer. As the US recommendations point out: 'Caution should also be taken to prevent excessive use of multivitamin supplements..... containing vitamin A, since excess vitamin A may cause birth defects.' Even if folic acid capsules are made freely available, an education programme would be required. Many scientists researching neural tube defects believe that fortification of staple foods with folic acid is the only effective way to reach those most at risk women from deprived backgrounds, with poor diets and a high incidence of unplanned pregnancies.

No sense of urgency

Progress is slow. The US Food and Drug Administration is still considering recommendations made last November to develop regulations allowing appropriate staple foods to be fortified. Foods on sale in the US labelled 'enriched' must contain specified amounts of various supplements, and one suggestion is that folic acid be included among these. But even if this is agreed, the question still remains, how much folic acid to add.

In Britain, most cereals contain enough folic acid to give about a quarter of the daily dose now recommended. But there is only one branded bread, Mighty White, which has added folic acid. The government has urged the Federation of British Bakers, whose members make about three-quarters of British bread, to inform its members about the recommendation to fortify bread. All members were sent a copy of the report early this year, though Tony Casdagli, director of the Federation, describes the idea as 'a slightly strange request. Usually', he says, 'the pressure comes the opposite way, wanting us to take things out rather than put things in.' Casdagli remains pessimistic about the scale of the bakers' likely response. 'They are disinclined to add folic acid other than in breads they are promoting as particularly healthy', he says.

Nicholas Wald, professor of environmental and preventive medicine at St Bartholomew's Hospital in London and a member of the Department of Health's expert committee on folic acid, says: 'The government has a responsibility that goes beyond just informing manufacturers about the options.' Wald accepts that legislation would not be in keeping with government policy and instead suggests that an advertising campaign be launched along the lines of the cot death initiative. 'If the government said "make sure the bread you buy is fortified with folic acid" then manufacturers would feel left behind if they didn't offer such a product.'

But even if manufacturers can be persuaded, the introduction of artificially high levels of folic acid to the food chain is bound to have its critics. There remains some uncertainty about the optimal dose, so the aim is for a supplemented diet to contain at least 0.4 milligrams, but not more than 1 milligram. Above this level folic acid may mask pernicious anaemia - a disease resulting from vitamin B12 deficiency. Normally this is identified early and then easily cured with a supplement of the deficient vitamin. In anticipation of such problems, Hall and other scientists working on neural tube defects have called for the establishment of a new agency. This would monitor the way in which folic acid is added to food as well as investigating doses and safety.

With improved nutritional standards and prenatal diagnostics, the number of babies born with spina bifida and anencephaly is already on the decline. As ASBAH's Tony Britton points out: 'The general public needs to be made aware that very simple steps could reduce the incidence even further.'

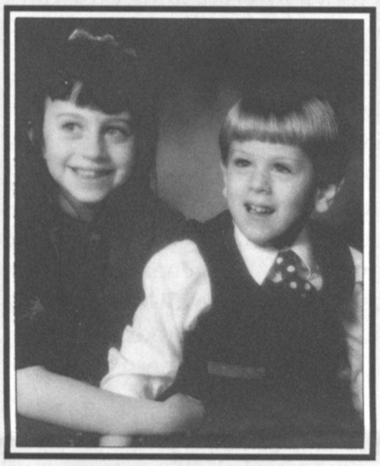
Kate Douglas's article first appeared in New Scientist on 17 July 1993.


Breakfast on folic acid!

Family Matters

The phrase 'the handicapped family' was coined some time ago - is it appropriate? How are the siblings of a disabled child affected? LINK hears from three families, Teresa Cole considers a new book on the subject, and two siblings tell their own stories.

THE GUSTAVINA FAMILY



Our son David, who has spina bifida and hydrocephalus, is three and a half years old and his sister Catherine is six. Although, owing to the inevitable hospital stays (three months when David was born) and numerous hospital visits/appointments, Catherine has been left with friends quite a lot, I don't think she has suffered in any way. The important thing is to include them in what is going on. She knows about David's condition and, as well as being very protective of him, they are good friends and love each other dearly. Although there have been times when David has required all our attention we have always been aware of the possibility that Catherine could be neglected or lose out in some way. This has *therefore helped us to make an* extra effort to ensure that this does not happen - in particular, making sure that we spend some quality time with her, doing what *she* wants to do.

Many people consider that insufficient attention has been paid to the effect on siblings of a disabled child in a family. There seems to be little for parents and siblings to use if they are interested in pursuing this subject. The welcome formation of MENCAP's sibs group in 1981 gave an opportunity for siblings themselves to have a voice and initiatives like this can only be helpful to any sibling who wishes to open this subject up.

Despite the findings in studies such as that undertaken in 1978 by Bristol University - that the presence of a child with severe disabilities had "quite extensive repercussions for the siblings" - the response that LINK received from families to the request for comments indicated that they considered there were few, if any, adverse effects. On the contrary, it was felt that the effects had been positive, good for the family: siblings were more caring and understanding. Some parents pointed out that some problems may have been identified by researchers as the direct result of having a disabled child in the family but would have occurred anyway between siblings of non-disabled children.

This anecdotal evidence would seem to be supported by, among others , a 1988 report published in the *Journal of Pediatric Psychology* which indicated that children adjust differently, whether or not they have a handicapped brother or sister. Other factors are at work, apart from the disability itself - family size, age spacing, socio-economic status and the mother's education have all been found to play a part. So, too, does the temperament of the non-disabled sibling.And the survey carried out in 1992 by the Disability Study Unit on relationships of children with their disabled brothers and sisters presented similar findings.

A recent book published in America - *The effects of Mental Retardation, Disability and illness on Sibling relationships: research issues and challenges* edited by Zolinda Stoneman and Phyllis Waldman Berman - follows the subject of sibling relationships further and merits considering at some length.

Based on the papers given at a conference held in the USA in April 1991, sponsored by the National Institute of Child Health and Human Development, this book claims to summarise the current state of knowledge in the field, whilst proposing challenges to future study. *(NB: this has adopted the terminology of the book, without reference to questions of political correctness or differences between UK and US usage.)*

In the first chapter, the editors set the scene by touching on the wide range of situations, experiences, and difficulties likely to be encountered by families which include a child with mental retardation, disability or chronic illness. Much research has tended to concentrate on the mother/child situation and there is little knowledge of the factors influencing relationships between the disabled child and its non-disabled brothers and sisters. Furthermore, there is a need for considering sibling relationships over the whole lifespan rather than concentrating on childhood and adolescence. The research outlined in this book seeks to redress this imbalance in approach.

The early chapters, grouped under the sub-title "Conceptual Issues in Research", whilst maintaining a fairly broad approach, introduce some specific themes. These include the attitudes of younger non-disabled siblings, the effect of mental retardation on adult sibling relationships, and the question of non-disabled sibling response to out-of-home placement. This last situation is identified as an area where lack of support is commonplace and families tend to be excluded from the "care networks".

Also included - and most welcome - is a chapter devoted to contemporary studies on sibling relationships between non-disabled children. This permits critical comparisons to be made so that the effects attributable to disability can more easily be recognised.

The next five chapters - sub-titled "Research Perspectives" - deal in some detail with sibling relationships involving specific disabilities. Many unanswered questions are identified, as are several topics for much-needed future research.

The last five chapters - "Methodological Issues for Future Consideration" - describe some issues needing further research.

Whilst this section will be of primary interest to researchers, it constitutes only a small part of the book and thus should not discourage the non-researcher.

The concluding section of the book identifies those common trends which run through the various

THE PATERSON FAMILY

I have three children, aged 13, nine and almost six. My husband died of leukemia in 1991 so we are unusual in several ways. My eldest son was born with the corpus callosum unformed and with multiple cysts, so has had a shunt since the age of six months. He has (I believe) several characteristics of a hydrocephalus-only person, but is also unable to balance so is wheelchair-bound and has poor use of his hands. Despite dismal predictions from the specialists, he has progressed far beyond expectations and is talking fluently (too often and too loudly!) and mostly coherently, and reads aloud with obvious understanding, although his choice of reading material is whimsical, the *Book of Common Prayer* being a current favourite. He is definitely idiosyncratic!

When I asked the middle brother what he would do to 'improve' Arthur, he thought he didn't mind the wheelchair - in fact his friends liked going for rides in it when they visited - and he didn't think he had lost any friends by having a disabled brother (in fact, they're all very kind to Arthur and don't ignore him) but he would like him to talk more sense and to stop teasing. (Arthur has an innate ability to sense touchy issues and weak spots, and to go for them.) When I pointed out that a 'normal' older brother would do this equally callously, he settled for Arthur being less vocal in public - joining in overheard conversations between people we don't know, especially - and being less dogmatic about TV programmes. (They usually agree, however.)

The youngest, a girl, wanted him to stop echoing me when I tell her to do, or not to do, something. "You heard Mummy, now get your coat on", etc.,etc. This winds her up, which encourages him to elaborate further. He gets very upset if I lose my temper with either of his younger siblings, and has been known to make a scene himself to distract me from being cross with them. Then we all have to calm each other down, so it's fairly subtle, and he's taken the pressure off them.

I think they appreciate him enormously and I encourage horseplay within reason. Both younger children lead full independent social lives and, apart from forgoing family holidays (I would not consider a solo week with three kids to be a restful way of spending a lot of money!) I do not feel that they are losing out.

Arthur does RDA carriage driving fortnightly (to a certain amount of healthy envy from the other two) and has a super LINK family whom he visits regularly. We have very generous friends who have shared holidays with us (an extra adult, especially male, to lift Arthur makes an amazing difference) and my late husband's sister and family, about 40 miles distant, keep in contact.

Arthur is generally well-liked. He seems to have cast himself into an "eccentric uncle" role, but is self-possessed and deliberately causes a great deal of amusement. It can be wearying, but it could be so much worse.

individual chapters. These indicate: a strong interest in the effect of caring on the sibling carer as well as the care receiver; the importance of viewing siblings' care in a whole family context not in isolation; the importance of lifespan researches; frustration at the lack of means to measure fundamental concepts such as stress, coping strategy, family adaptation; the need for obtaining family and sibling information directly from the disabled and mentally retarded.

In conclusion, the book successfully makes the point that an understanding of the effect of disability on sibling relationships is of major importance both for the well being of disabled children and for their non-disabled brothers and sisters.

Such in-depth understanding can only be gained from systematic research: educational and clinical experiences with siblings cannot lead to such understanding, only to insights.

Among researchers, fundamental differences in approach need to be resolved. Is it valid, for example, to take a general or disability-specific view, or alternatively should the focus be upon those common factors which span most disabilities - degree of physical mobility, intensity of care demand upon family, and so on? Such considerations will inevitably affect the way in which research is conducted into every aspect in this field.

One criticism - the book lacks summaries at the beginning of each chapter.

While chapters are to some extent summarised in the excellent preface , introductory summaries would have provided a valuable means of finding one's way around more easily.

To whom will this book appeal?

To the researcher in this field, it would seem to be essential reading and offers background ideas, guidelines and abundant references.

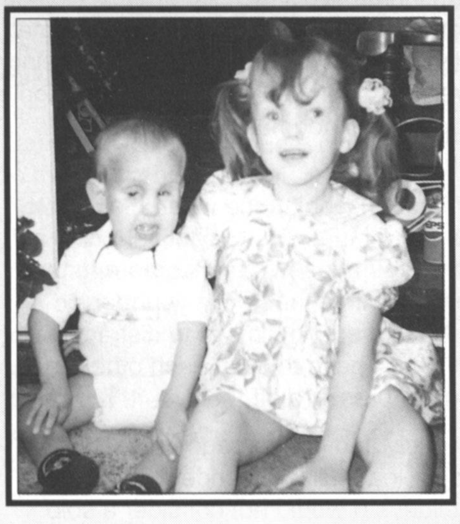
The professional in most disciplines will find much valuable information, probably indispensable if an understanding of this neglected topic is to be achieved.

For the parent who wishes to be well-informed and have up-to-date guidance, some perseverance will be worth the effort. The wealth of information it contains is not always easy to find. However, whilst not a textbook, it does have an index, enabling one to locate much specific information and inspiring some good guesswork in finding most of the rest.

In short no one could read this book conscientiously without learning a great deal about the subject.

Teresa Cole

THE HALLIWELL FAMILY



We have six children: two boys of 20 (yes,twins!), a boy of 16, a girl of 13, a girl of nine and a boy of six. The youngest two both have special needs. The girl has spina bifida and hydrocephalus; the boy is multihandicapped, but his biggest problem is that he is blind. These two were adopted and all our other children helped choose them through BAF books. I tell you this because I wonder if it has helped the older children in living with and understanding the younger two.

But the effect of having two disabled children on the family has been so good that I can recommend it to anyone! My children are more understanding, more tolerant, more caring towards the human race. They have grown to realise that people mean more than goods. Please don't get me wrong - they still ask for computers and so on. But when given the choice of extra money to spend on goods and adopting another child - enter James.

My daughter has been in hospital a lot for new shunts and has just come out after having an operation to fit rods in her back. This could have upset the rest of the family but I am lucky in having a mum and dad who will come and keep the house running smoothly and *spoil* the other children while I am away. This has taken the worry of hospital away from the older children and has also made them more independent and self-reliant as Mum is sometimes at the end of a phone instead of in the kitchen!

All our six children are different and all have needs - as a family we try to meet our own needs and those of each other. The word 'disabled' does not come into our vocabulary. It is only used by people who visit our home, but not by our friends. Perhaps this has helped all our children, I don't know. I just know it works well for us.

And our youngest two give us all so much love and pleasure in helping them achieve - we don't have problems any more, just achievements!

Never a dull moment!

This story is based on my real life experiences with my brother David, but I have changed some things a little bit to make it fit into a day, otherwise the story would have gone on forever!

By Angela Burslem, aged 9

"Saturday. Great! No school!"

It was half past seven - time to get up. I quickly got myself washed and dressed. Then I went into David's bedroom. David was wide awake but wouldn't get out of bed. "No want to get up!" he said. Eventually, with mum's help, I managed to get him up. Together we took David into the bathroom to give him a wash. But first of all he had to go to the toilet. Some days he sits on the toilet for ages, just for the fun of it. I think today was one of those days!

"Now let's get dressed," I said. "First your vest, then your underpants, then your socks, then your shirt." David did his best to help. "Now let's put on your trousers. Oh you silly billy - you've put both legs down one trouser leg ! Last of all let's put your jumper on" David picked up his badge which says "Now I am 8" on it, so I pinned it onto his jumper. He got it for his birthday and he likes it.

After breakfast we started getting ready to go shopping. "Where's David? You little rascal! You've sneaked upstairs to eat toothpaste again! Now you've got a little white line round your mouth and I'll have to wash it off!"

At last we were ready. David insisted on shutting all the doors in the house before we left. He always does this! We all piled into the car and set off for the shops. We parked near the sops and walked to the fruit shop. We went into the shop. Dad went to get one thing and me and mum another. We took our eyes off David for a few seconds. In a flash he was off to the car. Of course, he couldn't get in, so he started shouting "Want a wee wee!" which is what he always shouts when he's frightened. A man felt sorry for him so he took him to his house to the toilet! Meanwhile, back at the shop, panic-stations - where was David? Me and mum looked near the shop, while dad went back to the car. Just as dad got to the car David came out of the man's house. The man said, "He's OK. I've taken him to the toilet." Dad was so bewildered he just took David and said, "Thanks." Relieved, we got back into the car and went home for dinner.

After dinner we got into the car again and drove to the swimming baths. We got changed and got into the water. Then, before we could stop him, David had swum up to a man and started stroking his beard which was immensely long and thick! Dad apologised to the man, and explained that David likes beards. The man laughed, and said he didn't mind.

When we got home we had tea. We asked David to say grace. Then an amazing thing happened. David said his usual grace - "Thank you Lord Jesus for this nice food" but he added "and nice swimming" of his own accord! We were all delighted as he had never done this before. That proved that he doesn't just say his grace parrot fashion!

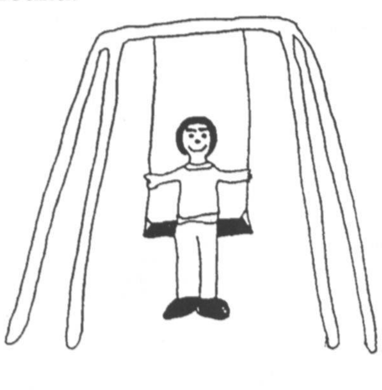
After tea we had a playtime in the sitting room. On the way to the sitting room David put our shoes carefully in what he thought were the rightful places in the hallway. He doesn't like to see anything out of place! Then he had two paddy-wacks on the trot! The first was because I had put a Mister Men tape on, and he wanted Postman Pat. The second tantrum was because he didn't want to play with his Duplo when I asked him to. How I hate David's tantrums! It's even worse when we're in public and everyone stares at us - I feel so embarrassed. In the end I gave in to him and put the Postman Pat tape on, and played rough and tumble with him, which he really enjoys. Afterwards I tried to get him to play on his own for a bit so I could read my book. But it didn't work. He kept annoying me. In the end I sat and had cuddles with him. I was a bit cross, but I didn't really mind because I like David when he cuddles me.

A bit later I had a talk with my mum. "Mum, it's not fair! I want so much to go to the Flight Museum but I can't because of David. We couldn't take him there - he just wouldn't behave", I said. "Well, I've got a surprise for you", she answered. "David's going to stay with his respite carers next weekend." "Oh great! Does that mean we can go to the Flight Museum then?"

"Yes, and David will enjoy staying with his respite carers - they're really nice."

By now it was bedtime. David started his usual routine of collecting all his seven toys to take to bed - a teddy, two enormous building blocks,a toy steering wheel, a musical sponge,a squeaky Ed the duck and a deflated beach ball! Then he tried to carry them all upstairs at once! In the end I carried Ed the duck, the building blocks and teddy. Then we had a wash and went to bed. Just as mum was tucking him in David shouted, "Want kiss Angie", so I had to get out of bed and give him a kiss.

That night I lay awake for a little while, thinking about the problems we have with David because he is autistic and has learning difficulties. But I love my brother and I laughed to myself as I thought about his antics this weekend. There's certainly never a dull moment when David's around!"



(A longer version of Angela's story appeared in Sibs autumn 1991/1992.)

A little brother, a lot of guilt

By Sara Wheeler

WE ONCE had a fight, I remember, over who pushed the trolley in Sainsbury's. I suppose I was about eight, which would have made him between six and seven. I can still hear the hard adult voice, remonstrating: "What a selfish girl you are - think of all the things you can do and he can't! Let your brother push the trolley!"

This is not an argument that an eight-year-old understands, but I believe it has the power to inculcate the kind of guilt that settles on the psyche like superglue. Twenty-four years later, at 32, I've only just begun to chip away at it.

Let me tell you another story. When I was 15 my best friend stayed the night at our house after a party. In the way younger brothers do, mine came into our bedroom at some brutally early hour and stood at the foot of my friend's bed, chattering. "Piss off, Matty," came the voice from under the duvet. This was my happiest adolescent memory: she was treating him like anyone else's little brother. It made me feel normal, and God that felt good.

Mathew was probably born with a fully operational brain, but it was damaged when he was a baby. My parents never found out how: it could have been the result of a whooping cough vaccination at nine months, or complications during his very swift birth, or some kind of fever.

In the Sixties healthy kids weren't allowed into children's wards. With my outdoor coat still buttoned up, I used to press my nose against a big glass door stencilled with long words in green paint. By the time he was five the family were so weary of hospitals and tests that the search was laid to rest and Matty freed from his torturers.

Mathew's intellectual development was slow; slower than most children in learning how to wash, dress and look after himself; at the age of seven he still needed the attention normally accorded to a three-year-old. Day-to-day activities took longer than they should have. He was also hyperactive and emotionally volatile.

Mathew absorbed a disproportionate amount of our mother's time. I was generally left, not disagreeably, alone with my book and Fuzzy-Felt while Mathew was prepared for an expedition into the threatening world outside our flat. From an early stage it was taken for granted that I was quite capable of tackling whatever task was at hand. After all, compared to him, I *was* all right.

I honestly do not remember resenting him, however much I search my heart. But I really must have.

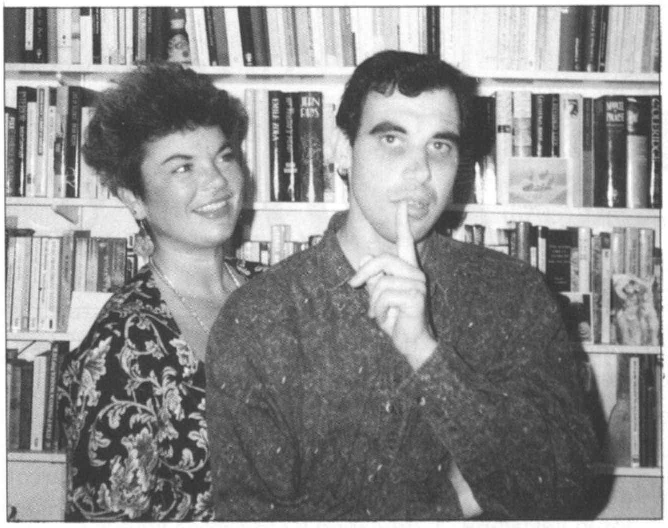
What I want to say is this. As the sibling of a handicapped child you are likely to feel resentment, dislike and even hatred, and you will probably feel guilty about doing so. I think the psyche turns this morass of pain into something quite other, so that it is no longer recognisable. Then, like me, you don't have to remember the shameful feelings. Into adulthood I marched, carrying heavy emotional baggage I couldn't unpack.

When I was at primary school, having friends home was a nightmare. Mathew always wanted to come into my room and join in. I was ashamed that he was "different" and didn't want him there; my little friends couldn't cope with his odd behaviour.

Mathew's frequent migraines were another embarrassment. They often occurred half-way through a special occasion, such as a birthday party; they usually involved turning all the lights out (to ease the pain) and clearing vomit off the carpet. I still have difficulty coping when happy occasions come to an end; I got stuck in a pattern of them ending badly.

I was always highly motivated. Nobody in our street could believe it when I got straight As and an exhibition to Oxford. This commitment was a gift from Mathew. But somewhere in my subconscious I had to allow myself to be weak, and in that murk I floundered. An eating disorder was one manifestation of my efforts to satisfy unmet childhood needs.

Mathew lurched from special school to special school before settling at a Steiner place we all liked. He didn't board until his mid-teens. I can't actually remember much about those years, which is probably significant in itself. I do know that in the holidays, we always had to head for places where everyone else wasn't: the empty cafe, the deserted corner of the park, the holidays in camper vans.



Sara Wheeler pictured recently with her brother Mathew. Sara's travel book about the Greek island of Evia, ***An Island Apart****, is available as an Abacus paperback. The story of her six-month odyssey in Chile,* ***Travels in a Thin Country****, is published in hardcover by Little, Brown in January 1994. This article from* ***The Independent****.*

Mathew is physically perfect: six feet tall and very handsome, with dark hair, dark eyes, and a muscular and slim body. He celebrated his 30th birthday last year, lives in a converted stately home run by an independent trust (his local authority pays) and works on a farm for the intellectually handicapped. He has just done a sponsored walk and raised £100 towards a minibus for handicapped children in Romania. He cannot read or write, or go out alone, or use money or the telephone. He knows how to enjoy himself, and is tremendous fun to be with. Although he can still be unpredictable, his behaviour is not as erratic as it was when he was 25, when he was still likely to lie down in the supermarket or hit our mother in public.

He often says directly what the rest of us conceal. At my home recently he met, after 10 years, a girlfriend of mine whom he had seen frequently throughout our teenage years. "Lyn!" he cried immediately and joyfully. "Do you like me?"

I can put my hand on my heart and say that I feel lucky to have him. I don't feel guilty about wishing there had been more of us; I think other brothers or sisters would have helped me. I feel angry that nobody ever explained anything to me or acknowledged that as "the other child" I had special needs, too. I didn't hear the phrase "the handicapped family" until I was 29: it hit me like a ton of bricks. We had a name! Earlier this year I discovered that MENCAP runs a sibling support service for adults. I was pitifully thrilled someone had recognised that a childhood like mine does have implications for adulthood.

I feel happy with the way my life is turning out: I love my work as a travel writer very much. But I am frightened of intimate relationships, a difficulty that may be connected to my childhood, and I wonder if it is any coincidence that I am still single.

The important thing for the adult with a handicapped brother or sister is to recognise the burden of resentment and pain, and work at freeing yourself of it. I was amazed at how much this (very lengthy) process helped me to understand myself. I hope that siblings who are children today do not have to drag that confused and needy inner child into adulthood.

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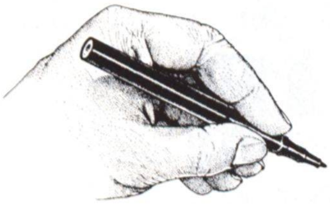

Letters

■ Our 15-year-old son Ryan took part in the Lifeskills Development Course at Beaumont College in July.

In the past we could not get Ryan to talk to disabled people, let alone mix with them so we took him on the understanding if he did not like it we would fetch him home. He has never been anywhere with anyone who is disabled before and this has bothered us but Ryan just would not go to see anyone or to see if there were any activities he might like to do.

When we arrived on Sunday he said he was not stopping. He said he felt disabled with other disabled people around and not disabled when around able bodied people. We told him just to look around anyway and, after about an hour, Ryan decided to give it a go! We were proud of him for making that decision but even prouder when we fetched him home. We could see the difference in Ryan right away. He was full of confidence, not only about what he had achieved with his wheelchair but in himself also.

Ryan is a very sensible 15-year-old and has been making decisions about operations and things like that for a while now but this certainly was one of the best decisions he has made in a long while.

Mrs J. Brooks, Pinxton, Nottinghamshire.

■ The following is a number of questions and comments inspired by LINK April/May '93.

Firstly, your article (page 10) on Gait Analysis reveals what seems a most useful procedure although the intent of the author or practitioners seems completely illogical and probably harmful. You first assume (from the way I read the article) there is some great benefit from being in a wheelchair, then ask "...whether they (patients) should be encouraged to walk". *Whaaat?* I believe any right thinking person, be they parent, helper or hospital staff would want someone with spina bifida to try to walk as best they can, as far as they can!

Let's face reality for a moment: it is an able-bodied person's world. We compete with them, not the other way round. To not encourage children to attempt walking, no matter how hard or painful is, in my opinion, to badly restrict their freedom and independence. To provide what looks like a softer option where exertion would provide greater rewards is a betrayal not a kindness. I do not claim to be a paragon of achievement, but through my mother's determination I left special school to enter the world of mainstream education. I have recently graduated with a BA (Hons) Degree in Communication Studies. I doubt I would have reached this far if I had been in a wheelchair. Education and the world is step-oriented (despite major efforts to the contrary). Of course people should be encouraged to walk up those steps!

Congratulations to Mary White, Lucy and Carol Moorhouse who did go the distance. Like Lucy I suffered from incontinence with all that involved. I was advised to go to Sheffield, which is something of a centre for spina bifida. I was introduced to self-catheterisation at Lodge Moor Hospital. A few years before taking my degree, I underwent an operation to expand the bladder and install a sphincter pump system. The result of this is that I am now dry for about SIX hours despite exercise etc. I now enjoy swimming and shorts in the "summertime" (i.e. 20 August!) Is this operation widely known about? Should it be?

Finally, an alternative to the alternative therapy of acupuncture. Shiatsu Massage does much the same thing as acupuncture, but without the needles. Acu-points are relieved by the masseur's thumb-pressure. It seems as effective and possibly a more relaxing method of relieving pain, tension etc. Like acupuncture it also seeks to heal the whole person rather than treating the body (and individual) as bits to be put back together again. I can recommend it!

David Fulford-Brown, Allandale, Blackpool.

Your letter makes a number of points to which I would like to reply. The issues that surround the image of using of a wheelchair are many - enough , indeed, to form the basis of an article in the next issue of LINK. I would appreciate any other readers' thoughts on David's letter and I'll try to include them. Let's hear from you!
John Naudé

■ Congratulations on the feature and on obtaining the two photographs of two veterans! (LINK August/September pp 20-21).

Just for the record, I was not the first Hon. Secretary, but the second one. I often wonder what became of the real pioneer, Tudor Williams, who lived at St. Albans, Herts. I replaced him at the first AGM, *after* the Constitution (Membership and Articles of Association) had been drawn up and engraved in tablets of stone, for better or worse!

Frank Armour, Horsham, West Sussex.

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